The Art of Grief: 
An Autoethnography Exploring Sibling Bereavement 

by 

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cc 
Tiffany T. Hill, 2019
COMMITTEE APPROVAL

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Final approval and acceptance of this thesis is contingent upon submission of the final copy of the thesis to Royal Roads University. The thesis supervisor confirms to have read this thesis and recommends that it be accepted as fulfilling the thesis requirements:

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Abstract

In this autoethnography, I explore my lived experiences of the dying and death of my brother and my grief in the six months following his death; reflect on my use of creative arts-based methods to shape and guide my grieving process; cultivate an understanding of grief as a process to be honoured as opposed to a problem to mitigate; and inform policies and practices to support siblings who are bereaved. The questions that guide the study are: (1) What are my lived experiences of the dying and death of my brother and my grief in the six months following his death? (2) How do creative arts-based methods support grieving processes? (3) How can my lived experiences of the dying and death of my brother and my grief in the six months following his death inform research and practice? My lived experiences are told as stories: my need to know and remember. Recommendations include: practice caution and compassion; recognize categories and labels as potentially problematic; offer resources to support goodbyes; and engage in ceremonies and rituals to support grieving processes. Recommendations of my study are designed to provide guidance for researchers, practitioners, and survivors of a loved one’s death.

_Keywords:_ autoethnography, creative arts-based methods, dying and death, sibling bereavement, grieving process
Dedication

In loving memory of my brother, Theodore Terence Hill. Theodore died peacefully in the loving arms of his family at Royal Columbian Hospital in New Westminster, British Columbia, Canada, the same hospital in which he was born, at 7:29 pm on Friday, November 24th, 2017. In his 33 years, Theo shared much laughter and many good times with his family and friends. He loved music and dancing and believed in enjoying the finer things in life. His big smile and gregarious laugh endeared him to many.

_In times of terrible tragedy, it can be helpful to look for the light and humour. And one thing that brings a smile to my face is the glee that I know Theo will feel watching me publicly praise and affirm him._ (Hill, 2017, para. 2; see Appendix A)

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1 Throughout this thesis, the name Theodore is intentionally identified with the font Consolas as a reminder of the significance of my brother within my research. This font was commonly used by him in his personal writings.
Acknowledgements

*Be around the light bringers, the magic makers, the world shifters, the game shakers.*

*They challenge you, break you open, uplift and expand you. They don’t let you play small with your life. These heartbeats are your people.* (Doby, n.d., para. 1)

Thank you to those who generously held critical roles in my lived experiences of the dying and death of my brother and my grief. Without you, this thesis wouldn't be possible.

My family *Mom, Dad, and, Tristan* - for openly sharing this journey with me.

My person *Julia* - for your profound and unwavering ability to be in it all.

My forever love *Kiana* - for loving me endlessly through every imaginable human emotion.

My supervisor *Cheryl* - for championing the evolution of my work and boundless possibilities.

My committee *Robin* - for encouraging and challenging me to rise to the occasion.

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Table of Contents

Abstract ............................................................................................................................................. 4
Dedication ......................................................................................................................................... 5
Acknowledgements ........................................................................................................................ 6
List of Figures .................................................................................................................................... 10
List of Acronyms ............................................................................................................................. 11
Chapter 1: In the Beginning .......................................................................................................... 12
  1.1 Definition of Terms ................................................................................................................ 14
  1.2 Organization of Study ............................................................................................................ 14
Chapter 2: My Context .................................................................................................................... 17
  2.1 Who Am I? ............................................................................................................................. 18
  2.2 What Happened? .................................................................................................................... 20
  2.3 What Do Others Say? ............................................................................................................. 29
    Disclaimer ................................................................................................................................. 29
    Introduction ............................................................................................................................... 29
    Sibling bereavement .................................................................................................................. 30
    Violent and traumatic death ..................................................................................................... 31
    Complicated grief ...................................................................................................................... 32
    Lived experiences ....................................................................................................................... 33
    Alternative views of grief ......................................................................................................... 34
    Continuing bonds ...................................................................................................................... 34
    Meaning-making ....................................................................................................................... 35
    Saying goodbye ......................................................................................................................... 36
    Death ceremonies and rituals ................................................................................................... 36
    Creative expressions and therapeutic interventions ............................................................... 37
  2.4 Chapter Summary .................................................................................................................... 38
Chapter 3: My Process ..................................................................................................................... 40
  3.1 Research Objectives and Questions ....................................................................................... 41
  3.2 Ontological and Epistemological Framework ....................................................................... 42
  3.3 Methodological Framework .................................................................................................. 42
    Autoethnography ..................................................................................................................... 42
    Arts-based research .................................................................................................................. 43
  3.4 Research Design ..................................................................................................................... 44
List of Figures

Figure 1. When we were young. Manila, Philippines. 1992. .......................................................... 12

Figure 2. Pewter heart, by T. T. Hill. New Westminster, BC. 2017. ..................................................... 17

Figure 3. The last time I saw you, by T. Zialcita. White Rock, BC. 2017. ........................................ 19

Figure 4. Painting in the sunshine, by T. T. Hill. Victoria, BC. (Hill, 16/5/2018)............................ 40

Figure 5. The truck, by T. T. Hill. Burnaby, BC. (Hill, 16/2/2018)...................................................... 52

Figure 6. Back in the distance, by T. T. Hill. Burnaby, BC. 2018. (Hill, 16/2/2018) ...................... 57

Figure 7. Embers, by T. T. Hill. Victoria, BC. (Hill, 14/12/2017)....................................................... 60

Figure 8. Quayside love lock, by J. Urquhart. New Westminster, BC. 2017................................. 63

Figure 9. The all-star classics, by T. T. Hill. New Westminster, BC. 2017........................................ 64

Figure 10. His heart, by T. Zialcita. New Westminster, BC. 2017. ..................................................... 67

Figure 11. His heart, Excalibur, and the crown, by T. T. Hill. Victoria, BC. 2018. .................... 68

Figure 12. Teenage boy, by T. T. Hill. Victoria, BC. (Hill, 21/3/2018) ............................................. 69

Figure 13. Heart of the storm, by T. T. Hill. Victoria, BC. (Hill, 29/12/2017)............................... 71

Figure 14. Braiding sweetgrass, by K. Alexander. Ladner, BC. 2019. ............................................. 75

Figure 15. Embracing uncertainty, by T. Zialcita. New Westminster, BC. 2017. .................... 93

Figure 16. The power of a single story, by K. Goodwin. Victoria, BC. 2018................................. 99
## List of Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>BC</td>
<td>British Columbia</td>
</tr>
<tr>
<td>ICBC</td>
<td>Insurance Corporation of British Columbia</td>
</tr>
<tr>
<td>ICU</td>
<td>Intensive Care Unit</td>
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<tr>
<td>MA</td>
<td>Master of Arts</td>
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<tr>
<td>MVA</td>
<td>Motor Vehicle Accident</td>
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<td>MVF</td>
<td>Motor Vehicle Fatality</td>
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<tr>
<td>PAR</td>
<td>Participatory Action Research</td>
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<tr>
<td>PI</td>
<td>Private Investigator</td>
</tr>
<tr>
<td>RCMP</td>
<td>Royal Canadian Mounted Police</td>
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<td>RRU</td>
<td>Royal Roads University</td>
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Chapter 1: In the Beginning

Owning our story can be hard but not nearly as difficult as spending our lives running from it.

Embracing our vulnerabilities is risky but not nearly as dangerous as giving up on... the experiences that make us the most vulnerable. Only when we are brave enough to explore the darkness will we discover the infinite power of our light.

(Brown, 2010, p. 6)

Figure 1. When we were young. Manila, Philippines. 1992.

Puff Daddy (ft. Faith Evans & 112) - I’ll Be Missing You
Chapter 1: In the Beginning

On Friday, November 24th, 2017, my brother, Theodore, died an unexpected death. His death is now part of my story; a story that at times feels insufferable. Yet, through this research, I discovered, contrary to popular belief, that suffering may hold goodness, learning, and beauty. This is my story; an honest and true representation of my lived experiences.

In this autoethnographic research study, I explore my lived experiences of the dying and death of my brother and my grief in the six months following his death; reflect on my use of creative arts-based methods (i.e., creative writing, music, poetry, painting, and photography) to shape and guide my grieving process; cultivate an understanding of grief as a process to honour as opposed to a problem to mitigate; and offer recommendations to inform policies and practices to support siblings who are bereaved.

The following research questions guide my study:

1. What are my lived experiences of the dying and death of my brother and my grief in the six months following his death?
2. How do creative arts-based methods support grieving processes?
3. How can my lived experiences of the dying and death of my brother and my grief in the six months following his death inform research and practice?

Through an understanding of my own lived experiences; my Master’s research seeks to extend knowledge about a cultural and societal phenomenon (Méndez, 2013) and demonstrate how self-reflection and personal narratives, like my own, can contribute to the literature, knowledge, and practice of dying, death, and grief. As well, I hope my research supports those who are grieving or who have or will experience grief and loss in their lifetime.
1.1 Definition of Terms

Within my thesis, I define key terms as follows:

**My brother’s dying** refers to the time I was notified my brother was in an accident (22 November 2017 at 3:30 pm) to the hour and a half before his time of death (24 November 2017 at 5:59 pm).

**My brother’s death** refers to the hour and a half before his time of death (24 November 2017 at 5:59 pm) to the 15 minutes after his time of death (24 November 2017 at 7:44 pm).

**My grief** refers to the six months from the time I was notified my brother was in an accident (22 November 2017 to 22 May 2018).

**Survivor** refers to a person who has survived the death, accident, and/or suicide of a loved one.

1.2 Organization of Study

My study is organized into eight chapters. At the beginning of each chapter, I offer a quote/poem, image, and song; all of which are artistic additions to the corresponding chapter. Readers are encouraged to listen to the songs to better understand the mood and tone of the chapter. For a comprehensive “Remembering Him” music playlist, see Appendix B.

Throughout the thesis, my brother’s name Theodore is acknowledged with the font Consolas; a font commonly used by him in his personal writings.

**Chapter 2** begins with a brief introduction to who I am and where I come from. I then offer a first-person narrative on the dying and death of my brother; the story is an account of what happened in the events that led to my brother’s death. A review of the literature on what other scholars say follows. Literature explored includes keywords such as sibling bereavement, violent and traumatic death, complicated grief, lived experiences, alternative views of grief,
continuing bonds, meaning-making, saying goodbye, death ceremonies and rituals, creative expressions, and therapeutic interventions.

**Chapter 3** introduces an overview of the research methodology and methods, including ethical considerations. In particular, I discuss autoethnography and creative arts-based research, the two methodologies used throughout the research and grieving process.

**Chapter 4** and **Chapter 5** share my research findings through a series of stories. These stories convey elements of my lived experiences of the dying and death of my brother and my grief in the six months following his death. Throughout these chapters, *italicized* words represent direct quotes from creative products (data) such as journal entries and reflections. Within every story, I offer findings and my reflections on my lived experiences.

Specifically:

**Chapter 4** tells the story of my need to know. I present the facts given to me about the accident that led to my brother’s death. I offer my reflections on how knowing these facts, and in ways, I learned and expressed them, promoted reimagining the accident, experiencing relief, and learning the limitations of language.

**Chapter 5** tells the story of my need to remember. I discuss the rituals, ceremonies, and creative expressions with which I engaged to honor and remember my brother. Ceremonies presented include: saying goodbye, visiting place, viewing body, mourning and celebrating life, and witnessing cremation. Rituals explored include: listening to music, tattooing, creating stories and poetry, painting, and receiving gifts of gratitude. I then offer my reflections on how rituals, ceremonies, and creativity encouraged me to find comfort and get closer to my brother in my grieving process.
Chapter 6 offers a discussion and recommendations contextualizing my lived experiences with literature introduced in Chapter 2. My recommendations include: (1) practice caution and compassion; (2) recognize categories and labels as potentially problematic; (3) offer resources to support goodbyes; and (4) engage in ceremonies and rituals to support grieving processes.

Chapter 7 concludes with summaries of my stories and recommendations, study outputs, limitations and significance of the study, and implications for future inquiry.

Chapter 8 ends with an epilogue capturing my final thoughts.
Chapter 2: My Context

Standing in loss but not overwhelmed by it, we become useful and generous and compassionate and even amusing companions for others. But solace also asks us very direct and forceful questions. Firstly, how will you bear the inevitable that is coming to you? And above all, how will you shape a life equal to and as beautiful and as astonishing as a world that can birth you, bring you into the light and then just as you are beginning to understand it, take you away?

(Whyte, 2016, p. 219)

Figure 2. Pewter heart, by T. T. Hill. New Westminster, BC. 2017.
Chapter 2: My Context

This chapter provides context to better understand my research including a description of who I am, what happened in my lived experiences of my brother’s dying and death, and what others say about research related to these lived experiences. I begin this chapter with an introduction to my positionality as a researcher. Subsequently, I offer a first-person narrative on the dying and death of my brother; the story is an account of the events that led to my brother’s death. A review of the literature regarding what other scholars and researchers posit follows. Literature explored includes keywords such as sibling bereavement, violent and traumatic death, complicated grief, lived experiences, alternative views of grief, continuing bonds, meaning-making, saying goodbye, death ceremonies and rituals, and creative expressions and therapeutic interventions. The chapter concludes with a summary.

2.1 Who Am I?

My name is Tiffany Tresa Hill. I am a storyteller, sister, world traveler, philosopher, avid concert goer, and owner of big feelings and many tattoos. I was born in Vancouver, British Columbia (BC), Canada, but as an infant and toddler, was cared for by relatives in Alabang Muntinlupa, Manila, Philippines. As a small child, I moved back to Canada and am fortunate to be a guest on Coast Salish territory. I am grateful to the Musqueam, Squamish, and Tsleil-Waututh peoples for allowing me to create a life, learn and play on their ancestral and unceded territories. My parents emigrated from the Philippines to Canada and divorced shortly into my childhood. I grew up with two brothers, Theodore and Tristan, and also have a half-brother and two step-siblings. Although I come from a seemingly large family, only recently have I begun exploring what the sibling bond means to me.
My desire to explore dying, death, and grief for my research was initially sparked in 2013 through my volunteer work with Canuck Place Children’s Hospice (Canuck Place) in Vancouver. As a family support volunteer, bereavement support volunteer, and in-home support volunteer, I had the privilege of developing relationships with children with progressive, life-threatening illnesses, their families, and other families who have experienced the death of a child. In supportive group settings, I witnessed the power of play, art, music, and recreational activities to support children and families to navigate dying, death, and grief. I was inspired to better understand how the lived experiences of children whose siblings died could inform policies and practices to support them. As such, my initial Master of Arts (MA) research intended to engage children whose siblings had died, aged 12-16, to explore their lived experiences and enhance bereavement services for children provided by Canuck Place.

Amidst the development of my graduate research, my brother, Theodore, died an unexpected death. Consequently, I chose to shift my research to focus on my own lived experiences navigating the complexities of his dying and death and my grief. Reflecting on the
meaning of suffering, Frankl (2006) noted: “for what then matters is to bear witness to the uniquely human potential at its best, which is to transform a personal tragedy into a triumph, to turn one's predicament into a human achievement” (p. 112). The impetus to conduct this research originates from the hope and confidence that by gaining insight into the story of my own lived experiences of grief, this body of work can serve as a point of connection, story, and resource for those who have or will experience grief and loss in their lifetime.

2.2 What Happened?

Pause and Reflect: This section explores graphic details of my brother’s death and my experiences with his dying. Readers may find these details challenging and potentially triggering. The invitation is to continue reading holding your own wellbeing in mind.

**My story.** It’s been 27 hours and 44 minutes since I last heard from him. “I think I’m okay now,” he said, and I’d believed it. I’m sitting at my desk in a concrete building at the university campus where I work. My cell phone rings and I answer. It’s a social worker from Royal Columbian Hospital.

“Is this Tiffany Hill?” she asks.

“Yes,” I respond.

I hear the words *brother*, at the *hospital*, in a *severe accident*, and his identification found *near* him. I live on an island, a beautiful island; but an island approximately four hours away from where I used to call home. I’m left speechless, not quite computing the conversation.

“Is there anyone else that can identify him?”

“I think so… maybe my *little* brother? My mom? My dad?”

I give her their contact information and immediately ask for more details.

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2 Throughout this thesis, *italics* are used to represent direct quotes; however, in this section (2.2), *italics* are used to emphasize important words in the narrative.
“Once we’ve identified that it’s your brother, I am able to tell you more,” she says.

“But if it is my brother… should I be there?”

She doesn’t say yes, but she doesn’t say no. The call lasts precisely five minutes. It takes me another minute to walk out of the office and make my next call.

The drive to the ferry terminal is ominous and silent. My roommates never leave my side, providing both comfort and adamant reminders about the more practical things, like water and food. In the lineup to board the ferry, the next dreaded call came. This time it was a familiar voice, my little brother, Tristan.

“He’s not going to survive,” he says.

The terminal is a large room swamped with strangers and the sound of my cries fill the space. My knees buckle, I sink into the seat next to me, and my phone falls from my face. The curious crowd of people begins to board the ferry and eventually, somehow, with a little help from my friends, my legs bring me up the ramp and onto the boat. The ride is too long. I’m in and out of phone calls; there are so many more questions than there are answers. I feel sick, numb, and helpless.

As the ferry docks, I am met by my friend Julia, the faint laughter of her 3-year-old, and the deep snoring of her 3-month-old. As we embrace, tears fall from the corners of my eyes. Off to the hospital, we race. When we arrive, I walk into the emergency room where I approach and ask for Theodore.

“He’s been moved to ICU,” she says.

I follow the signs and the closer I get, the more familiar faces I start to see. My mother, tear-stained, embraces me and begins to trail into half explanations before she’s politely interrupted by the presence of a woman sent from Victim Services. When your family member has been in a
terrible accident, you learn what Victim Services is -- a program dedicated to the needs of familial survivors. I motion her towards an emptier, more private corner of the massive hall.

“I want all the facts. What happened? How did it happen?” I ask.

Before her exact recollection of the state of events, she offers a few words of condolences. Words that seem strange coming out of her mouth.

“We received a call from a witness reporting a man behaving strangely on the sidewalk. He was seen rolling around, then started taking off his clothes, and jumped into oncoming traffic,” she says.

“Here’s ‘the more’ I wanted,” I think to myself.

“The tires of the truck crushed his skull repeatedly, a second car hit him, and a small crowd gathered. At this point, it’s considered an ongoing investigation of attempted suicide.”

My reaction is reasonably calm; yet my thoughts are heavily clouded and confused.

My family is escorted to the ICU where a Family Room awaits us. The room feels somewhat sterile: a few seats, side tables, and pull out couch-like contraptions. We barely make it into the room before we're whisked away to a smaller meeting room with more strangers. My mother sits to my right, my father to my left, both holding onto me. Tristan sits silently with a fairly blank expression on his face. The strangers introduce themselves as the doctor, nurse, and two interns.

“I’m so very sorry…” the doctor says.

“As you know, Theodore was in a severe accident and as a result, he has very little brain function and will not survive.”
I do already know this; yet, as it comes from the doctor’s mouth it feels all the more real. Amidst the soft sobs of my parents, still clinging to process, I interrupt with:

“What’s next? What are our options? What do we do?”

The doctor encourages us to take our time with the next steps. Persistent, I finally get him to disclose information on exploring organ donation. I politely ask the medical team to leave the room. As a family, we discuss the option and they gracefully oblige.

“Is that what he wanted?” my father asks.

“There’s no way to know,” I respond.

The conversation is relatively short, disturbed only by the bickering of my parents over the kind of coffee my father bought for my brother before the accident. Was it 711? Tim Hortons? At this moment the answer feels like it really matters, though I’m not sure why. I catch Tristan’s eye amidst the squabbling and we both laugh, silently reminiscing over how dysfunctional their bickering felt when we were children. After almost two decades of their broken marriage, this is what it takes to reunite.

The doctor comes back into the room and we ask that he calls the organ donation specialist team. Without thought or discussion, I’m given a piece of paper that reads ‘Declaration of Substitute Decision Maker’ giving me legal authority to make all decisions about my brother’s medical care. To them (and others) I am the decision-maker, the leader, and what my parents called, ‘The President’. I’m left behind in the room, shaking, to sign the paperwork and confirm next steps.

The four of us slowly walk past the medical board where ‘Hill’ is written and turn the corner in front of bed #16 where he lay. At first glance he is supine; he could simply be sleeping, if not for all the machines connected to his body. I muster up all the courage I have to walk into
the room. As I step forward, I get a better look at his face -- or what barely resembles the face I knew him to have. *His eyes are swollen shut, a white towel over his head, and a yellow brace around his neck. Both his arms lay by his side, he’s draped in a hospital gown and his knuckles are battered.* I reach out to touch his arm, he *feels warm to the touch.* I mutter a few words and excuse myself.

I wait an hour and a half until the specialists arrive. It feels like time is frozen. My parents, Tristan, and I collectively agree to be the only ones to see my brother in his current state. The four of us return to the “family room” which is now ironically filled with strangers aside from a few familiar faces. Tristan and I both instinctively turn to sit outside the room with our people.

“There’s no room for me in there,” he says.

How could there be no room in a room designated for us? Another hospital anomaly. Over the next few hours family, friends, and more strangers pour in. Everyone sits around waiting, but I’m not really sure what they are waiting for. My parents reminisce about what it was like to be in love over 30 years ago. I find this to be deeply ironic: my parents have been divorced for 15 of those 30 years and have barely been able to be in the same room since. In the middle of my parents’ awkward flirtatious reminiscing, my brother’s nurse appears in the hallway.

It’s 10:30 pm and the specialists arrive. The nurse escorts me, Julia, and her sleeping son attached to her back, into the meeting room. With a soft demeanour, she introduces herself and gives me an overview of the procedures involved with donating my brother’s organs. First, I consent to which organs and tissues I’d like donated. ‘I, Tiffany Hill, sister of Theodore Hill, give consent to…’ I check *all of the above.* His eyes. His liver. His lungs. His kidneys… Then, his organs and tissues will be tested to deem if they are viable. If viable, they will look for
matches. Once matches are found, they will take my brother off life support. Then we wait. For the transplant to happen he will have to be declared dead within two hours from the time the machines are turned off and he is left to breathe on his own. As these instructions are drilled in my head, all I can think about is who are they and what does she mean dead?

“This process will take up to 48 hours,” she says. She hands me the paperwork. Exhausted, I agree to sign the forms and revisit the logistical procedures in the morning.

I go back into the Family Room and update everyone on what’s next. They all agree to go home and sleep and as I intend to do the same, I ask my brother’s nurse if she thinks it would be okay to leave to sleep. She responds that although she in normal circumstances recommends families rest, she also conveys how fragile my brother’s state is. I just keep thinking to myself that ‘he can’t die alone.’ So, I stay.

Julia and her baby stay too. They sleep on one pull-out chair and me on the other. We have a few blankets; bright hospital lights fill the cracks of the doors. The door next to our room is accessed by a card reader. Throughout the night, every time someone swipes a card, my eyes open and I imagine my brother’s nurse coming into the room. It never actually happens. 7 am can’t come soon enough.

The next morning finally appears, yet in the hospital, it all feels the same. Tristan and my dad arrive late, bringing with them the waft of fast food for breakfast. I am released and leave the hospital to rest. Unsurprisingly, rest is far from what happens. After a few hours of experiencing traumatic shock -- a series of shaking, dissociation, hysterical crying, and feeling physically ill -- I find my way back to the hospital to finish what I started. In a much more stoic state, I’m asked:

“Can you tell me if your brother was sexually active?”

“Well…” I begin to trail.
As promised, a woman from the organ donation team arrives to ask me several intimate questions about my brother’s life. With half a chuckle, I tell her about his fondness for fine dining, drinking, and drugging. She reassures me that his youthful age gives his liver a fighting chance. After her series of questions, I ask for explicit details about what happens next.

“At 6 o’clock tomorrow night, we’ll ask you and your family to step outside his room as we remove his tube. We will take him off all machines except one that will monitor his heart. You will be invited back into the room and from then on, he will have two hours to die on his own in order for his organs to be viable to donate. If Theo chooses to keep fighting, it may be his way of letting you know he just wants more time. And that’s okay.”

What a strange concept. Willing my brother to die to save lives. She continues:

“When Theo is ready, a doctor will announce his time of death. At that moment, you will have two minutes to say your final goodbyes, and they will bring him to the operation room just around the corner.”

Struck by the reality of what the next 24 hours will bring, I walk back into the waiting room and witness Tristan being bombarded with questions -- borderline interrogations -- from our extended family and friends. He keeps repeating what he was told:

“It’s an ongoing investigation of attempted suicide.”

He’s factual, to the point, and detached. The only glimmer of emotion he extends is anger towards my parents, who continue to tell their own version of events. My dad is hopeful, seeking a miracle, and fixated on the details of his last interaction with my brother. My mom is surrounded by her friends, most of whom are people I’ve only met for the first time. She is also active on social media which inevitably infuriates us all. I turn to Tristan and say,
“I know it’s frustrating, but this is just how she’s grieving. We’re all going to do this differently.”

Heeding my own advice, I gather our family and discuss the details of our goodbye tomorrow. Sitting in a circle, one-by-one, we express our greatest fears and comfort one another. I’m convinced none of what I said lands. I just hope that when the moment comes, we’re all prepared as much as we can be.

I visit bed #16 again before leaving the hospital to have my first proper meal since arriving -- a tuna poke bowl from Brown’s Social House. *Weirdly comforting.* After my meal, I go back to my friend’s house for another attempted rest. Instead, my restlessness leads me to the shower where I continue to grapple with how to create space for others to connect with Theo. And, as the water runs over my body, I think about ways they can say goodbye.

“I need cards and pens,” I announce, wrapped in a towel and freshly drenched in water from head to toe.

At the hospital, I put out the cards, pens, and a black box, along with a note encouraging friends and family to write words for me to read at Theo’s bedside. And with that, I leave the hospital.

The next morning, I take my time to get ready, dressing in my Sunday best and slowly applying makeup. All the while, I contemplate why my Sunday best is so important. I get to the hospital and I collect what feels like hundreds of cards. With cards in hand, my family and I make our way to Theo’s room. *Upon entry, his eyes are open without seeing, skin visibly more yellow, and body still warm to touch.* I sit near Tristan while reading every card, Facebook message, text message, e-mail, and words of goodbye from people near and far. As I read every word of goodbye out loud, I’m convinced Theo hears us and he’s savouring every moment. During the next few hours, my mom hangs out at his feet, my dad on his right and I on his left.
Tristan refuses to touch him, but he does move closer to take a picture. Together, we *sing, dance, cry, reminisce*, and *laugh* one last time.

It’s now 6 o’clock and the doctors have yet to arrive. I text Julia, who is stationed at the waiting room, to tell her that we’re behind schedule. She replies by sharing that our friends and family are gathered in circle connecting, praying, honouring, and holding us in their thoughts. As more waiting ensues, the nurse overhears a conversation Tristan and I are having about adding to my collection of many tattoos. Minutes later, the nurse hands us a printed copy of his echocardiogram. Elated, we thank her, and my parents join the conversation about our elaborate plans to get inked. Time feels like a standstill.

It is 7 o’clock when the doctors and organ donor team finally arrive. As planned, my family and I step out of the room as the team of doctors proceed to take him off life support. They remove the tube from his mouth and we hear him gasp for air. My family and I form a circle outside of his room; we share tears as my mom recites:

“Started from the bottom, now we’re here,” a 2013 hit from Drake and Theo’s favorite lyric to quote.

Before I know it, we’re escorted back into the room. We all naturally resume our positions around Theo who is connected to one standing machine with the sole purpose of monitoring his heart. *I have my head on his chest, hear his heartbeat slow in pace, and feel the sensation of his hand letting go of mine; yet, where his hand lays remain unchanged.*

“He’s gone…”

And just like that, the doctor announces 7:29 pm as his time of death.
2.3 What Do Others Say?

**Disclaimer.** A literature review specific to sibling bereavement in childhood was originally formed as part of my initial research study prior to my brother's death. Although it is specific to childhood bereavement and participatory action research (PAR), it greatly influenced my adult perspective and understanding of my brother’s dying and death, as well as the methods I used to facilitate my own grief process.

Recognizing a traditional thesis typically has a literature review formed prior to conducting the study (Creswell, 2014), traditional structures are less common in autoethnographic studies (Adams, Holman Jones, & Ellis, 2015; Adams & Manning, 2015). To support my iterative and emergent research process, I have instead developed my literature review while conducting the study. Below, I focus on key concepts related to my lived experiences of the dying and death of my brother and my grief.

**Introduction.** Sibling loss is the least researched of all familial loss (Rostila, Saarela, & Kawachi, 2012). The limited research that does exist on sibling loss focuses mainly on the pathology of grief (Cicirelli, 2009; Eaves, McQuinston, & Miles, 2005; Mash, Fullerton, & Ursano, 2013; Pretorius, Halstead-Cleak, & Morgan, 2010). As such, little is known about the needs and lived experiences of sibling survivors; in particular, what interventions and/or actions support sibling survivors with their grief and their lived experiences of navigating the continuing bonds and making meaning of the loss. Given the aforementioned gap in the literature, research motivated by the desire to understand comprehensive narratives is needed to better recognize the needs and lived experiences of siblings who are bereaved.

In this interdisciplinary literature review, I explore bereavement literature as it relates to siblings in adulthood. I examine literature relevant to my lived experience of my brother’s death;
as such, violent death and complicated grief are discussed. I then acknowledge the significance of exploring lived experiences and offer historical views of grief with emphasis on continuing bonds and meaning-making. I discuss the potential for rituals, ceremonies, and creative expressions to support grieving processes and, in particular, how they may support complicated grief and making meaning of loss.

**Sibling bereavement.** The death of a sibling represents the loss of a unique bond. The biological sibling bond is inherently unique because of shared genetic makeup (Zampitella, 2011) and strong emotional ties (Wright, 2017). The relationship may be a reliable source of support (Moss & Moss, 1989), a connection to family, shared lived experiences, and memories (Eaves, McQuiston, & Miles, 2009), and can be one of the longest lasting ties in a lifetime (Flecher, Mallick, & Song, 2013). Thus, the death of a sibling can be devastating and surface multiple hardships for the sibling survivor. In particular, sibling death in adulthood has its own distinct challenges. For example, the sibling survivor may face making decisions regarding end-of-life care and funeral arrangements and supporting family members while readjusting their own role in the family (Wright, 2017). Survivors of sibling death in adulthood may have unique needs that very little research has identified (Wright, 2017).

Most of the literature on sibling bereavement in adulthood focuses on the pathology of grief (Wright, 2017). Studies suggest adult siblings who are bereaved experience depression (Cicirelli, 2009; Mash, Fullerton, & Ursano, 2013), regret (Eaves, McQuinston, & Miles, 2005), shock and disbelief, guilt, fragmentation, anger (Pretorius et al., 2010), and are at risk for health complications (Rostila et al., 2013a, 2013b, 2013c). Yet, other more positive outcomes of sibling loss are also recognized, such as newly found personal strength and resilience (Pretorius et al., 2010), recognition of new possibilities (Taku, Tedeschi, & Cann, 2014), and a greater sense of
meaning in life (Mash et al., 2013) – all outcomes often described when referencing post-traumatic growth: the notion that difficult life struggles can lead human beings to change in positive ways (Calhoun & Tedeschi, 2014; Tedeschi & Calhoun, 2004). Although these positive outcomes are acknowledged in the grief and loss literature, more research is required to understand the needs of sibling survivors and in particular, what interventions and/or actions survivors need to support their grieving processes, including honouring both the suffering and the potential for positive outcomes.

**Violent and traumatic death.** Currently, research pertaining to violent death losses in bereavement more generally also primarily focuses on pathological aspects of grief (Wright, 2017). Violent deaths are “caused by human intent or negligence” (Armour, 2007, p. 55) and are commonly categorized as deaths resulting from motor vehicle accidents (MVA), suicide, and homicide (Armour, 2007; Currier, Holland, & Neimeyer, 2006). Research suggests that violent losses increase the risk for psychological suffering of survivors during the grieving process (Kaltman & Bonanno, 2003). Whereas there are many common symptoms survivors exhibit irrespective of the type of violent death, there are also distinguishing reactions they may exhibit. For example, survivors of motor vehicle fatalities (MVF) may suffer from rumination, a persistent, repetitive, and chronic focus on the occurrence, causes, and consequences of the death (Nolen-Hoeksema, 2001), physical health consequences, and phobias about travel (Armour, 2007). MVF are considered the most unanticipated of deaths and survivors of MVF report that the memory of how the news of the event was delivered to them has lasting significance (Armour, 2007).

On the other hand, survivors of death by suicide may struggle with a range of experiences including guilt for not saving their loved ones (Armour, 2007; Pompili et al., 2013),
understanding the “true thought process” (Armour, 2007, p. 65) and stigma and being misunderstood (Pompili et al., 2013). A study on the stigmatization of suicide bereavement suggested that survivors of traumatic deaths reported significantly higher levels of stigma than natural death survivors (Feigelman, 2009). Specific to sibling loss, one study interviewed 45 adult siblings bereaved by suicide and focused on how uncertainty and loss manifested in their perceptions and experiences (Powell & Matthys, 2013). The qualitative study conveyed the complicated nature of grief and concluded that survivors are often left with unanswered questions and a cognitive void (Powell & Matthys, 2013). As Buksbazen (1976) asserted, “it just remains a mystery that you can’t really let go of and that you can’t deal with because there’s nobody there to answer when you hit the right answer to the riddle” (p. 107).

Furthermore, literature has argued that regardless of the type of violent death, survivors struggle and often fail to find meaning in the meaninglessness of violent death and instead, and often need to disengage from the search for coherence in the story of dying (Ryerson, 2001). Due to the exacerbated challenges faced by survivors of violent deaths, survivors may have heightened vulnerability to psychological trauma and complicated bereavement (Currier, Holland, Coleman, & Neimeyer, 2008).

**Complicated grief.** According to Green (2000), complicated grief and traumatic loss (death that is sudden, unexpected, and violent) are interrelated and overlap. Prigerson and Jacobs (2001) described complicated grief (also known as traumatic grief and pathologic grief) as difficulty comprehending and accepting the death of a loved one, intense longing for the deceased, intrusive thoughts about the deceased, and avoidance of painful memories. In particular, studies suggest that higher rates of complicated grief occur in those who are bereaved by violent death (Mancini, Prati, & Black, 2011; Currier, Holland, & Neimeyer, 2006) and those
who are bereaved relatives of intensive care unit (ICU) patients (Anderson, Arnold, Angus, & Bryce, 2008; Siegel, Hayes, Vanderwerker, Loseth, & Prigerson, 2008).

Armour (2007) asserted that those suffering from complicated grief may obsessively “search for reasons or dwell on the missing details in an attempt to have the senseless loss make sense” and often feel “left with scraps of information about what may have happened” (p. 55). As well, basic assumptions about the world and beliefs about the goodness in people are challenged (Armour, 2007; Shear et al., 2011). Complicated grief literature proposes that although seemingly contradictory, both excessive avoidance and excessive proximity seeking (e.g., going places that are reminders of the loss) may be symptoms of complicated grief (Shear et al., 2011). Specific to sibling loss, a comparative study was conducted on complicated grief responses after the loss of a sibling in young adulthood (Mash et al., 2013). The comparative study concluded that participants who were siblings were more likely than those who were close friends to experience complicated grief, depression, somatic symptoms, lower sense of meaningfulness and compassion in the world, and a lower sense of self-worth (Mash et al., 2013).

**Lived experiences.** Although there are insights to be gained on studying the pathology of grief, grief is also a multifaceted lived experience. As Klass (2018) articulated, he was:

Reluctant to see pathology in grief as anything more than a cultural matter. That is, all cultures have guidelines for grieving and expectations of bereaved people. Underlying the viewpoint is that we should avoid drawing simplistic causal relationships and should be particularly careful when it comes to telling people how they should live and grieve (p. 6).
Lived experiences are complex, and merely looking at the negative mental and physical health outcomes of grief is problematic because grief reactions and experiences among sibling survivors span a wide range (Kübler-Ross, 1969). Therefore, there are benefits to understanding lived experiences in their entirety; such as, the potential to learn more about the needs of sibling survivors, rather than just their responses and reactions to grief.

**Alternative views of grief.** Historically, the study of bereavement has advocated for emotional detachment and severing bonds from the deceased in order to achieve closure (Packman et al., 2006), which was reinforced by the medical model that compared grief to a wound that eventually heals (Davies, 1999). Alternative views of grief have since observed grief as “work” (Worden, 2009); finding ways to weave loss into lives by continuing bonds (Klass, Silverman, & Nickman, 1996) and making meaning of loss (Neimeyer, 2001).

**Continuing bonds.** Klass and colleagues suggested that those bereaved may benefit from continuing attachment to the deceased in new circumstances (Klass et al., 1996), and this attachment was framed as continuing bonds. Although some of the early literature on grieving has suggested that moving on and letting go is a goal, more recent literature endorses an approach that suggests that moving on and letting go may be an unreasonable and unhealthy expectation (Neimeyer & Attig, 2001); instead, maintaining a connection may support working through the loss by relearning the world in a way that helps live with the loss (Attig, 2001) despite physical separation (Field, Nichols, Holen, & Horowitz, 1999). As such, scholars and practitioners have recommended survivors purposefully include the deceased in their ongoing lives (Packman et al., 2006). Specific to sibling bereavement, Hogan and DeSantis (1992) referred to continuing bonds as an ongoing attachment where sibling survivors desired a continued bond with their deceased siblings by reaffirming, catching up, influencing, and
reuniting. By contrast, other scholars have suggested that when siblings have conflictual relationships, continuing bonds may be disturbing or frightening (Normand, Silverman, & Nickman, 1996). Studies have also identified that within adult sibling bereavement, continuing bonds and unresolved or delayed grief may coexist (Cicirelli, 2009; Moss & Moss, 1989). In addition to continuing bonds to the sibling that is deceased, making meaning of death is also reported to support grief processes.

**Meaning-making.** Meaning-making is considered an activity that supports those who are bereaved in integrating the death of a loved one and moving forward (Neimeyer, 2001). This is often done by either making sense of the death, that is, finding reasons for why it happened, or by rendering a larger purpose or benefit to the death (Neimeyer, Burke, Mackay, & van Dyke Stringer, 2010). As well, meaning-making may be “making sense of the events leading to the death and around the death, making sense of our relationship to the deceased, and making sense of our ongoing lives after the death” (Morgan & Steffan, 2008, p. 37). The search for meaning after traumatic events is a common and essential task (Park & Folkman, 1997); yet, studies have shown that finding meaning occurs less frequently for survivors dealing with a violent death (Davis, Wortman, Lehman, & Cohen Silver, 2000; Murphy, Johnson, & Lohan, 2003).

Following bereavement and loss, meaning-making is essential for recovery and resilience (Bonanno, Wortman, & Nesse, 2004), relearning the world (Attig, 2001, 2011), and processes of meaning reconstruction (Holland, Currier, & Neimeyer, 2006; Neimeyer, 2001).

Further, research suggests that continuing bonds and meaning-making may be more difficult for sibling survivors who have lost siblings in violent and traumatic circumstances (Murphy, Johnson, & Lohan, 2003; Prigerson et al. 1999). As such, more inquiry is needed to understand how sibling survivors of violent deaths may continue bonds and make meaning of the
deaths of their siblings. In particular, exploring how rituals, ceremonies, and creative expressions may support the grieving processes of sibling survivors may be valuable.

**Saying goodbye.** Although several studies indicate that families that are bereaved feel that saying goodbye before their loved one died was important to them (Heyland et al., 2006), there is limited research exploring how families can best facilitate such goodbyes. This lack of understanding is particularly important when death occurs in the ICU of hospitals because families in this setting are reported to already exhibit feelings of anxiety and stress (Azoulay, Chaize, & Kentish-Barnes, 2014). Therefore, coupled with uncertainty and uneasiness, families are often faced with not knowing how to say goodbye to their loved ones and receive few (if any) resources. In addition, families may not have opportunities to say goodbye to their loved ones if their loved ones are unconscious and unable to respond, possibly leaving survivors feeling as though the goodbye is incomplete. Families may experience what can resemble a vortex (Kirchhoff, 2002); therefore, unsurprisingly, families reported a need for a comfortable place to say goodbye (Millner, Paskiewicz, & Donald, 2009) and support from nursing staff (Andrew, 1998). Most of this research that focused on ICU family care tends to concentrate on family satisfaction with care and pain management for the patient (Kirchhoff, 2002) and bereavement care after death (Nelson et al., 2010) as opposed to exploring ceremonial ways in which families can say goodbye to loved ones.

**Death ceremonies and rituals.** Literature related to death ceremonies and rituals often focuses on post-death. In particular, there is a wealth of knowledge regarding death practices related to funerals and memorials (Bäckström, 2019; Lobar, Youngblut, & Brooten, 2006), a body of practices that are mostttly influenced and informed by religion and culture (Lobar et al., 2006). For example, a study specific to Pacific island groups on cultural variations in response to
the process of dying and grieving suggested that Filipino Americans identify primarily with the Catholic faith which played a factor in choices to organize a funeral mass and burial post-death (Braun & Nichols, 2010). Other studies suggest that funerals are a way to express love and respect, continue ties (Kastenbaum, 2004), and bring people together (Hoy, 2013).

One particular study has also recognized post-funeral rituals that are less tied to church-based rituals of remembrance (Vale-Taylor, 2009). These activities include visiting the grave, revisiting places with special meaning, displaying and showing photos, sharing memories, lighting candles, listening to music, and creating (Vale-Taylor, 2009). Overall, ceremonies and rituals have the potential to offer those who are bereaved emotional comfort, a sense of belonging, and support in continuing bonds with their loved one who has died (Hoy, 2013; Vale-Taylor, 2009). Similarly, people who are bereaved may gain comfort through creative expressions (Thompson & Neimeyer, 2014).

**Creative expressions and therapeutic interventions.** There appears to be an inextinguishable human impulse to create in the face of loss that when acted upon, has the potential to support making meaning of the loss. This creativity can come in different shapes and forms, such as writing, painting, and generally just creating (Thompson & Neimeyer, 2014). For example, as both a creative and therapeutic modality, writing may give control in circumstances in which people who are bereaved seemingly have none (Doka & Martin, 2011), support the creation of a new life whereby creativity can help “fill the space left by the one who has died” (Moss, 2012, p. 13), and facilitate healing (Bolton, 2008a). Specific types of writing, such as auto/biography (Stanley, 1993), can serve a reparative rather than escapist function, helping to recreate a storied sense of what has been lost, a life story, a life disrupted by loss, a life cut short, or a life ending (Letherby, 2009; Thornton & Letherby, 2009). Writing can bring a sense of hope.
to those who are grieving by creating a narrative that helps them readjust to a changed reality rather than dwell in the destructive feelings of loss (Edgar-Bailey & Kress, 2010).

Not only do survivors engage in creative activities in order to make meaning of the loss, but creative therapeutic interventions also support acts of creation in order to support loved one’s continuing bonds with the deceased. Creative therapeutic practices and activities are foundational for working with children in bereavement (Edgar-Bailey & Kress, 2010); yet, less is reported about whether these practices can be transferrable to adults (Wright, 2017). These interventions often include play, art, music, movement, and drama (Edgar-Bailey & Kress, 2010; Malchiodi, 2015; Thompson & Neimeyer, 2014). In particular, in cases of survivors of violent deaths, Tedeschi (1999) observed that the shock associated with violence can be a catalyst for personal and social transformation and that “those who are in greatest despair and have felt most out of control are prone to transformative experiences while persons who are open to experience, hopeful, extroverted and creative make the most out of trauma” (p. 327).

2.4 Chapter Summary

In summary, I acknowledge that both who I am and my lived experiences influence my understanding of the literature I have reviewed. My perspective as a young, university-educated Filipino-Canadian woman with experience using creative arts-based therapeutic methods to engage with children whose siblings have died is significant to this autoethnographic study. Furthermore, as my story of the death and dying of my brother is the foundation of this work, I have provided a narrative to support my explanation of my positionality as a researcher. A review of the literature regarding sibling bereavement, violent and traumatic death, complicated grief, lived experiences, alternative views of grief, continuing bonds, meaning-making, saying
goodbye, death ceremonies and rituals, and creative expressions and therapeutic interventions followed. It is to this body of research that I ultimately hope to contribute.
Chapter 3: My Process

So too, whenever you kiss your child, sibling, or friend, don’t layer on top of the experience all the things you might wish, but hold them back and stop them, just as those who ride behind triumphant generals remind them they are mortal. In the same way, remind yourself that your precious one isn’t one of your possessions, but something given for now, not forever...

(Holiday & Hanselman, 2016, p. 349)

Figure 4. Painting in the sunshine, by T. T. Hill. Victoria, BC. (Hill, 16/5/2018)

Gavin James - The Book of Love
Chapter 3: My Process

This chapter outlines the design of my autoethnographic study, which draws on the strengths of creative arts-based methods to understand my lived experiences of my brother’s dying and death and my grieving process. I begin this chapter by restating my research objectives and key questions. I then provide an overview of my ontological, epistemological, and methodological framework. A description of my overall research design follows, including my research process, methods, data collection and analysis, and how I sought to ensure rigor and trustworthiness. The chapter concludes with an exploration of ethical considerations and a summary.

3.1 Research Objectives and Questions

My research sought to: understand my lived experiences of my brother’s dying and death and my grief in the six months following his death; reflect on my use of creative arts-based methods (i.e., creative writing, music, poetry, painting, and photography) to shape and guide my grieving process; cultivate an understanding of grief as a process to be honoured as opposed to a problem to mitigate; and inform policies and practices to support siblings who are bereaved. The following research questions guided my study:

1. What are my lived experiences of the dying and death of my brother and my grief in the six months following his death?
2. How do creative arts-based methods support grieving processes?
3. How can my lived experiences of the dying and death of my brother and my grief in the six months following his death inform research and practice?

By taking an autoethnographic approach, I sought to inform the practice of those who work with people who are grieving or those who have or will experience grief and loss.
3.2 Ontological and Epistemological Framework

My research takes an ontological and epistemological position that acknowledges and values lived experiences and different ways of knowing. As such, I am a social constructivist with a transformative orientation who believes that lived experiences support humans to make sense of their worlds (Ellis, 2004). Rather than conducting my research from a neutral, impersonal, and objective place, my research is subjective and emotional, renouncing rigid definitions of what constitutes meaningful and useful research (Wilson, 2008). Moreover, the orientation of my research is supported by Jung’s understanding of knowledge as thinking, feeling, intuition, and sensation (1971). My research uses nonconventional methods that give shape to what I know, feel, intuit, and sense about my lived experiences of the dying and death of my brother and my grief.

3.3 Methodological Framework

Autoethnography. Autoethnography is an approach to research that “seeks to describe and systematically analyze (graphy) personal experience (auto) in order to understand cultural experience (ethno)” (Ellis, Adams, & Bochner, 2011, para. 1). Autoethnographic research: (1) acknowledges the value of personal relationships; (2) uses reflexivity to understand self and society; (3) is rigorous while incorporating emotion and creativity; and (4) facilitates social justice (Adams, Holman Jones, & Ellis, 2015). This methodological approach also supports personal reflection on lived experiences in a systematic way (Wall, 2008).

Autoethnography was a natural methodological choice for my MA research because I wanted to explore my lived experiences of my brother’s dying and death and my grief. The decision to use autoethnography was informed by the nature of the methodology, the context (my grieving), and the events that unfolded abruptly (my brother’s death). The approach was well-
suited to support my grieving process and my ability to complete my research, as well as validate my experience (Bochner, 2012). Further, autoethnography encourages the use of creative methods and permitted an emergent and open process (Ellis, 1998; Wall, 2006); rather than requiring me to adhere to conventional research methods, which can be overly objective, distancing it from my true human experience (Denshire, 2014; Wall, 2006). Lastly, autoethnography facilitated an ongoing learning experience (Chatham-Carpenter, 2010) and a process of meaning-making (Adams & Ellis, 2012), which resonated with me in relation to my grieving process. Autoethnography is considered a suitable methodological approach when exploring grieving as an ongoing process of meaning reconstruction and transformation that will have a long-lasting personal impact (Greenspan, 2003; Neimeyer, 1999; Neimeyer, 2000; Neimeyer, Burke, Mackay, & van Dyke Stringer, 2010).

**Arts-based research.** My approach to autoethnography was informed by arts-based research. Arts-based research is “an effort to extend beyond the limiting constraints of discursive communication in order to express meanings that otherwise would be ineffable” (Barone & Eisner, 2012, p. 1). Instead of endorsing a singular interpretation of reality, arts-based researchers persuade the audience and participants to reconsider the world from different directions by encouraging them to look beyond the surface of what is familiar (Barone & Eisner, 2012). An arts-based orientation to my research supported my needs and evolving capacities through my grief process (Thompson & Neimeyer, 2014), and mirrored best therapeutic practices and tools used to support those who are bereaved (Edgar-Bailey & Kress, 2010; Thompson & Neimeyer, 2014). Arts-based research captured glimpses that reflect the complexity and diversity of my lived experiences of my brother’s dying and death and my grief (Barone & Eisner, 2012), and acknowledged I have valuable insights to share.
3.4 Research Design

**Research process.** The research process was iterative and emergent, with me as the subject and my grieving process as the object of inquiry. I reflected on my own personal experiences with my brother’s dying and death and my grieving process. To explore my lived experiences, I used: creative writing (i.e., free writing, journaling, writing narratives, and found poetry), music (Daykin, 2004; Wheeler & Murphy, 2016), poetry (Chilton, Gerber, Councill, & Dreyer, 2015), painting (Thompson & Neimeyer, 2014), and photography (Renzenbrink, 2014). Creative products were coupled with my reflections and observations as sources of data; all of which were supportive of, and integrated into, my grieving process. Sixty-seven artefacts were gathered including 55 written reflections, one narrative (see Chapter 2, section 2.2), one eulogy (see Appendix A), one found poem (see Appendix C), one playlist (see Appendix B), five paintings (three of which are presented as Figures 4, 7, 12, & 13), and three photos (two of which are offered as Figures 5 & 6). Due to the nature of the research, flexibility was required (Adams et al., 2015) and other methods that were not proposed initially emerged throughout the research process. Data analysis was performed in two stages: inductive and deductive coding and a comparative analysis was engaged.

**Research participants.** Given that my lived experiences are the focus of my research, I am the participant of inquiry for my study. I mention other members of my family e.g., parents, siblings, and friends in my thesis; however, these people are not considered research participants because the focus of my study is on my own lived experiences.

**Creative arts-based methods.** To gather and collect my data my methods include creative writing, music, poetry, painting, and photography. I explore these methods from the day my brother died (November 24, 2017) to six months after his death (May 24, 2018). Although
the focus of my research reflects this timeline, my grief process continues and is a much longer process.

**Creative writing.** To engage in creative writing, I explored four specific methods: free writing, journaling, writing narratives, and found poetry. I describe each one herein.

**Free writing.** This method involves writing continuously for a set period of time while ignoring traditional grammar rules (Hill, 2010; Reeves, 2010). I engaged with this technique to keep from editing my thoughts and because free writing is found to “relieve tensions and to moderate periods of confusion, conflict, and anxiety” (McKinney, 1976, p. 186). In some instances, the writing was directive (e.g., I asked myself specific questions about my experience) and at other times was less directive (e.g., I used no prompts and continuously wrote for a specified duration of time) (Reeves, 2010). The writing primarily occurred for periods of 10-20 minutes at different stages throughout the six months.

**Journaling.** I wrote thoughts, feelings, observations, and notable memories on a regular basis in physical journals and in digital form (Gregory, 2016). At times, journal entries were left incomplete. Journaling was used more frequently during the first few months of data gathering.

**Writing narratives.** I wrote a first-person narrative on the dying and death of my brother (Maynes, Pierce, & Laslett, 2008; see Chapter 2). This short story was supported by my journal entries and informal conversations with family and friends who were witness to the experience of my brother’s dying. I wrote reflections on the story I composed, gaining further insight into my lived experience (Greer, 2014; Schneiderman, 2015).

**Found poetry.** This is a process where one “take[s] existing texts and refashion[s] them, reorder[s] them, and present[s] them as poems” (Poets.org, 2004, para. 1). To create found poems, I gathered old conversations (i.e., text messages, Facebook messages and interactions,
emails) between my brother and myself and our journal entries (his were available as an online blog). In reviewing these communications, I highlighted words or phrases that resonated with me. Using these select highlighted words and phrases, I then wove them together to create a poem entitled “Found” (see Appendix C). The process of creating a found poem took place in month two (December 2017-January, 2018).

**Music and poetry.** Throughout my research process, I listened to music and read poetry to prompt thinking, feeling, and further reflection on my lived experiences of the dying and death of my brother, and my grief (Daykin, 2004). Musical artists such as Drake, Al Green, Gavin James, Labrinth, Ed Sheeran, and Sam Smith; and poets such as Maya Angelou, Ryan Holiday, Rumi, Richard Wagamese, and David Whyte, were significant for me. As a way to pay tribute to the importance of these artists and poets in my research process, I have integrated songs, poetry, and quotes into each chapter of my thesis. These are intended to enhance the reader’s experience by conveying emotion, tone, and feeling. A “Remembering Him” Playlist also emerged (see Appendix B).

**Painting and photography.** During my research process, I explored the use of painting and photography to make meaning of my brother’s dying and death and my grief. I created a series of paintings on a white canvas using acrylic and oil paints. All paintings evolved and changed throughout the six months and some remain incomplete. In month three (February-March, 2018), I took a photography course instructed by a dear friend. In the course, I focused on integrating new understandings and technical skills (i.e., exposure, composition, lighting, etc.) into creating photographs relevant to my grieving process. During the process of creating paintings and photographs, I reflected on the meaning made through these processes and on how they supported my grieving process (Jennings, 2014; Renzenbrink, 2014).
**Other methods.** Additional creative methods that supported my navigation of grief included digital storytelling (Fletcher & Mullett, 2016), pottery, mixed emotion cards (Martin, 2001), and tattooing (Hill, 2014). The outputs of these methods were not used as data for this research; however, they informed, shaped, and supported my grieving process.

**Data and data collection.** As stated above, to generate data, I used creative arts-based methods including creative writing, music, poetry, painting, and photography. The creative works produced through these methods were contextualized with my thoughts, reflections, and observations about the process; the meaning I made through these processes; and the ways each creative arts-based method supported my grieving process. All audio files capturing my reflections and observations were transcribed and all creative products were digitally copied. All data collected was stored securely in a password protected hard drive.

**Data analysis.** My process of data analysis can be described in two stages.

**Stage 1: Inductive coding.** (December 2017-January 2018): In the two months following my brother’s death I coded all of the data collected over this time period using colored highlighters and post-it notes. This process was a form of inductive coding. According to Creswell (2002), the process of deductive coding involves a read through of data, identifying segments of information, labeling the segments of information as categories, and narrowing down categories (Creswell, 2002). From these categories, I developed initial emerging themes.

**Stage 2: Deductive coding.** (January 2018-May 2018): With themes identified, I continued to collect and code data for an additional four months using an adapted deductive coding process. The process of deductive coding looked to add dimensions to themes that had emerged previously (Fereday & Muir-Cochrane, 2006). All stories that developed are not
presented in this thesis; only two are explored: my need to know and my need to remember (see Chapters 4 and 5).

Because autoethnography is not a conventional form of research, data analysis was not guided by traditional forms of analysis (Ellis & Bochner, 2000). Therefore, different forms of analysis were employed, including a comparative analysis that compares my lived experiences and process to existing literature on bereavement and grieving (Ellis, Adams, & Bochner, 2011) and highlighting relevant themes that have sociocultural and psychological significance relevant to understanding my experiences (Philaretou & Allen, 2006). My analysis is presented as a discussion of stories that are true to my lived experiences of the dying and death of my brother, and my grieving process.

**Trustworthiness.** Le Roux (2017) proposed that the trustworthiness criteria of an autoethnographic study include subjectivity, self-reflectivity, resonance, credibility, and contribution. My lived experiences of the dying and death of my brother and my grief cannot be replicated and are unique because of the subjective nature of my experience. I demonstrated an element of reflexivity in my practice through reflection, journaling, and challenging assumptions (Creswell, 2014); invited readers to “enter into, engage with, experience, [and] connect with [my] story on an intellectual and emotional level” (Le Roux, 2017, p. 204); established integrity and honesty in my storytelling and transparency of my process; and contributed knowledge to bereavement literature.

To further establish trustworthiness, my research used Kolb’s (1984) four-stage experimental learning cycle to: (1) describe my lived experiences of my brother’s dying and death and my grief; (2) observe and reflect on my lived experiences; (3) make connections to dying, death, and bereavement literature; and (4) offer recommendations for future experiences.
3.5 Ethical Considerations

**Compliance with ethical guidelines.** To ensure ethical considerations were followed, my research complied with the Royal Roads University, *Request for Ethical Review for Research Involving Humans* (2014) and the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2014). My research was approved by the Royal Roads University Research Ethics Board on 6 April 2018.

**Informed consent.** Although the autoethnographic approach to the research positions myself as the subject of the research, others including immediate family (i.e., my mom, my dad, and my younger brother), extended family, and friends were directly affected by my research. As such, I informed them of my research topic and methods, and potential risks and implications of the research, such as being identifiable (see Appendix D). Those identified in my thesis were notified that they would be mentioned in the research, they were given an opportunity to refuse to be named and were explicitly told that what was written in the research is from my perspective and not a representation of their thoughts, words, or experiences. Lastly, I provided them the opportunity to view a draft of the final report that highlights the specific points where they were mentioned before my thesis was submitted for final review. They were encouraged to offer their feedback, thoughts, and concerns.

**Confidentiality and anonymity.** Given the nature of the research, confidentiality and anonymity were not guaranteed; however, measures were taken to minimize the risk of harm to all people involved in my research, including myself (Denshire, 2014; Tolich, 2010). Accordingly, I discussed the concepts of confidentiality and anonymity with those identified in detail. In an aim to
safeguard their privacy, I gave them the option to not be identified by name when mentioned or referred to in the research, and they were given the choice to not be discussed in my research at all. All those identified chose to be discussed and named when applicable.

**Relational ethics.** Relational ethics refer to the inevitable connections and responsibilities that I have to the people in my research, and my obligation to uphold and consider ethical action (Adams & Ellis, 2012; Ellis, 2007a) to honour the rights of these people (Lahman, Geist, Rodriguez, Graglia, & DeRoche, 2010; Tolich, 2010). Thus, self-reflexivity was essential in doing the research. I considered carefully the information that had the potential to be harmful to members of my family or myself (Adams et. al, 2015; Ellis, 2007a; Wall, 2008). I also considered what I write about my brother, who is deceased, and therefore cannot give consent (Ellis, 2007a; Ellis, 2007b).

To support others who may be impacted by my writing, I have explained in detail what my research is about and have sought their consent to conduct this research. In addition, they were given the opportunity to review where they were mentioned in the thesis, in order to ensure that they are comfortable with what I had written about them. Because this research is focused on my own lived experiences, I did not ask my family and friends to review all of my reflections and the thesis proper.

**Personal safety and wellbeing.** The nature of this research topic may pose potential risks to my health and safety. These risks included surfacing difficult emotions (Denshire, 2014) and public scrutiny (Adams et al., 2015). Thus, I determined what I feel is ethical and safe for me to make public knowledge (Denshire, 2014; Ellis & Bochner, 2000; Tolich, 2010). As a proactive measure, I journaled throughout the research process and identified a network of colleagues with
whom to debrief including my Supervisor and Research Committee. As well, I regularly saw my counsellor throughout the duration of the research.

3.6 Chapter Summary

The design of my autoethnographic study of my lived experiences of my brother’s dying and death and my grieving process is grounded in creative arts-based methods. These methods were selected for their ability to capture the complexity my lived experiences of my brother’s dying and death and my grief (Barone & Eisner, 2012), and to provide a unique research perspective. My research process involved iterative, emergent, and reflective approach that incorporated creative writing, music (Daykin, 2004; Wheeler & Murphy, 2016), poetry (Chilton, Gerber, Councill, & Dreyer, 2015), painting (Thompson & Neimeyer, 2014), and photography (Renzenbrink, 2014). Both inductive and deductive coding was employed, and a comparative analysis emerged. The overall design prioritized trustworthiness, considering my dual roles as researcher and subject.
Chapter 4: My Need to Know

\[ i \text{ am sorry this world} \]
\[ \text{could not keep you safe} \]
\[ \text{may your journey home} \]
\[ \text{be a soft and peaceful one} \]
\[ - \text{rest in peace} \]

(Kaur, 2017, p. 125)

Figure 5. The truck, by T. T. Hill. Burnaby, BC. (Hill, 16/2/2018)

Jasmine Thompson - Follow Me
Chapter 4: Needing to Know

In this chapter, I discuss my first story which is centered on the theme of needing to know. I begin by presenting what is traditionally known as findings, in other words, what I identify as the facts and my reflections. I describe the facts given to me about the accident that led to my brother’s death. I then offer my reflections on how knowing these facts and in the ways I learned and expressed them, promoted reimagining the accident, experiencing relief, and learning the limitations of language.

Pause and Reflect: This chapter explores graphic details of my brother’s death, and while these reflect an accurate and critical component of my experiences with his dying, readers may find these details challenging and potentially triggering. The invitation is to continue reading holding your own wellbeing in mind.

4.1 Facts

My need to know the facts was a dominant theme around the dying and death of my brother. For me, facts included any information I could collect to offer a more coherent picture or understanding of reality or certainty (Hill, 18/12/2017); however, throughout my experience, my interpretation of facts and truth continuously evolved. Further, despite wanting to know the facts, I questioned how and why it was important to me to know. For example, in a journal entry I questioned, does it really matter if I know or don’t know? Does it change what happened? Does it change how I feel about it? (Hill, 4/3/2018). The answer was that it did matter, and although it did not change what happened, knowing it changed how I felt about what happened.

The facts about what happened to my brother on November 22nd, 2017, at approximately 12:45 pm, have always been, and will likely always remain, disturbingly unclear (Hill, 18/12/2017). In my journal, I recounted arriving at the hospital and listening to my distraught
mother struggling between cries to explain the events of the accident. I wrote *I couldn’t listen to her. I needed to know everything. The facts – objective, cold-hard truths. Not an interpretation of what she thought she knew* (Hill, 19/2/2018). I approached the victim services worker and asked her to tell me everything. In response, she said:

*they received a call from a witness reporting a man behaving strangely on the sidewalk.*

*He was seen rolling around, then started taking off his clothes, and jumped into oncoming traffic... the tires of the truck crushed his skull repeatedly, a second car hit him, and a small crowd gathered. At this point, it’s considered an ongoing investigation of attempted suicide* (Hill, 1/12/2018).

I asked myself what her words meant, suicide? *Like he killed himself? That can’t be right, there must be more to it than that* (Hill, 19/2/2018). In fact, there was more to it. At the same time, the victim services worker explained to me what happened, a photograph of the scene of the accident was also being circulated in the community. The photo was of my brother, lying on his side, naked, on the street, surrounded by a pool of blood and a crowd of bystanders and parked vehicles. The description attached to the photo read: *Asian woman’s dead body found in the middle of the road* (Hill, 26/12/2017). After a concerted effort to locate the photo, a friend tracked it down at my request and gave to me to view a few days after my brother died.

Three weeks later, I received an accident collision report from the Insurance Corporation of British Columbia (ICBC) explaining details about the collision. The report relayed information about the make, model, and year of the truck; the identities of the truck driver and the witness; the location of the accident; and other information that had been blacked out, or redacted. More notably, the report communicated different details than those that were conveyed
to me by the victim services worker at the hospital. *Only a truck, no car. Only a witness, no
crowd* (Hill, 18/12/2017). Answers still unclear.

Sixteen weeks after the accident, I received a phone call from a private investigator (PI). He was hired on behalf of ICBC to conduct a thorough investigation of the accident. The PI confirmed what I already knew was coming: *it was a deliberate act, and it was suicide* (Hill, 4/3/2018). He also confirmed the details of the accident collision report and offered new facts. According to the PI, there had been two 911 calls placed about the accident; one of which described my brother sitting on the curb of the sidewalk clutching a book. In my journal, I wrote, *I wonder what book it was. There were only three options he left for me to sort through after I
picked up his belongings from the police station. I wonder what he was thinking about... what he
read moments before* (Hill, 4/3/2018). The details of the events leading to my brother’s death were critical for me to know in order to move on: from reimagining the accident, to experiencing relief from wondering, and to learning the limitations of language.

4.2 Reflections

**Reimagining the accident.** As noted above, much of the information I received about the accident was inconsistent. Every time new facts were introduced, I was prompted to reimagine an alternative narrative and to accommodate the new facts into my understanding of what happened. In a journal entry, I wrote *I keep replaying the narrative I was given over and over
again in my head. Just like a scene in a movie. I can’t stop thinking about what happened, how it
happened, why it happened. And every new detail changes the scene* (Hill, 19/12/2017). This reflection highlighted how critical knowing details about the accident was to me because every detail warranted a change in the emerging narrative. For instance, when I heard the first iteration of the facts given to me in the hospital, I pictured a crowd of people witnessing my brother’s
erratic behaviours before the accident occurred. I questioned why no bystanders had intervened and contemplated how I could and would have stopped him if I had been there. Reflecting on these facts, I pondered: *It doesn’t quite make sense to me. There was time to stop him as he contemplated his life. How could people just watch something like this and be idle to it? How am I supposed to have faith in humanity after this?* (Hill, 15/12/2017). This particular detail mattered because it affected how I saw people and humanity more broadly, and further, supported me creating a potentially more complicated and challenging relationship with the world and my surroundings. Wherein I was left wondering about the callousness of people who could stand by and do nothing.

Once I learned, through the collision report and the PI, that there was: only one witness outside of the truck driver, an off-duty female police officer driving in her car with her young child; the crowd gathered after the accident had occurred; and there was only a truck and no car; I began to recognize *there really wasn’t anything anyone could have done, including me* (Hill, 4/3/2018). I stopped questioning the ‘what ifs’ and was able to lay the scene of the accident to rest; moving on was in the realm of possibility.

**Experiencing relief.** In addition to the inaccurate and contradictory ‘facts’ about the accident that led to my brother’s death, there were also many facts that could not be revealed by simply reading reports and talking to professionals. Many facts were unknown; many questions were unanswerable: where was he going that day, why did he jump in front of the truck, what was he thinking about when he did and was death his ultimate goal? In a free writing exercise, I wrote, *I needed to know everything I could know in order to stop obsessing and reeling over it. In order to feel some kind of relief from wondering* (Hill, 26/3/2018). In response, I sought facts that could answer some of these questions. In particular, I was motivated to answer
the questions that might be answerable or may offer some semblance of relief for me. For example, 12 weeks after the accident, I revisited the accident scene in the hope of uncovering some answers. The collision report was fairly vague about the location, noting an intersection on a long and busy street in the neighborhood my brothers and I grew up in. However, the photograph taken of my brother at the scene of the accident offered a visual, yet traumatic, point of reference that the accident report could not. Specifically, in the far-left corner of the photo, there was a sizable boulder partially hidden by grass. This boulder served as a landmark and helped me to find the exact spot where my brother’s body lay weeks before. With my camera in hand, I walked along the same busy street on which the accident had occurred and reflected on what the day might have been like for him.

![Figure 6. Back in the distance, by T. T. Hill. Burnaby, BC. 2018. (Hill, 16/2/2018)](image)

Visiting the accident site supported my grieving process by affording me the opportunity to create a new relationship with the place and where this journey with my brother’s dying and death began. *I didn’t need to avoid it anymore. And I didn’t need to understand more about the where* (Hill, 16/2/2018). I felt a sense of relief. To honour this experience, I showcased the photograph (see Figure 6) I took that day at a student photography exhibit with the description:
Back in the distance captures the location of the accident that led to my brother's unexpected death. It was on this road where he was hit as a pedestrian by a white semi-truck on November 22nd, 2017 (Hill, 2/3/2018). Publicizing the photo and story to the greater community offered me a supportive environment to share my art, a symbol of my understanding of the accident.

**Learning the limitations of language.** Knowing the facts supported me to accurately describe to others what had happened to my brother. This was important to me because rumours, stories, and photographs had been circulated within my community. As I shared my version of the facts with people, I felt a sense of control within an experience in which I had very little. By knowing the facts and being able to precisely communicate the facts, other people were influenced by their own interpretations of the language and facts shared. For example, many people used the term ‘suicide’ to describe what had happened; however, I found this to be problematic. By the very nature of the word, suicide implied my brother had made a conscious choice to die. I do not believe there is a concrete way to prove this true despite external sources, such as RCMP and ICBC, deeming it a suicide. The day before the accident, my brother reached out to me and shared that he thought he was having a *mild psychotic episode* (Hill, 29/11/2017); I believe his state of mind may have contributed to his actions leading up to the accident. In a reflection, I wrote, *maybe he thought he was a samurai preparing to slay the dragon. But the truck wasn’t a dragon and he wasn’t a samurai. Or maybe he was?* (Hill, 15/12/2017).

Ultimately, experiences and events are often less black and white than they are made out to be, and there is importance in acknowledging nuances and discrepancies in the experience to understand the bigger picture.
4.3 Chapter Summary

My findings have been conveyed through my first story which is focused on the theme of needing to know. Through this story, I explained the ways that facts about my brother’s accident were provided to me and how this impacted my ability to reimagine the accident, to seek and find some relief, and to comprehend the limitations of language in capturing essential details and critical nuances.
Chapter 5: My Need to Remember

The power of art is that it can connect us to one another,
and to larger truths about what it means to be alive
and what it means to be human.

(Levitin, 2006, p. 244)

Figure 7. Embers, by T. T. Hill. Victoria, BC. (Hill, 14/12/2017)

Pentatonix - Hallelujah
Chapter 5: Needing to Remember

In this chapter, I offer my second story rooted in my need to remember. I begin by discussing my findings which I present as ceremonies and rituals. Ceremonies discussed include: saying goodbye, visiting place, viewing body, mourning and celebrating life, and witnessing cremation. Rituals offered include: listening to music, tattooing, creating stories and poetry, painting, and receiving gifts of gratitude. To close, I share reflections on how ceremonies and rituals supported me to find comfort and get closer to my brother in my grieving process.

5.1 Ceremonies and Rituals

My need to honor and remember my brother was critical to my lived experiences of my brother’s dying and death and my grief. Throughout, I honoured my brother with ceremonies and rituals to celebrate and remember him. While the words ceremony and ritual are similar in meaning, for the clarity of this study, it is useful to make some key differences. Therefore, I offer the following definitions: ceremony refers to a single event in time that is used to honour someone who has died and ritual refers to an activity that occurs on multiple occasions to honour someone who has died.

Ceremonies.

Saying goodbye. After the accident, Theo was transferred to the Intensive Care Unit at Royal Columbian Hospital. Many extended family members and friends visited the hospital and gathered in the hallways and waiting room to show their support for Theo and our immediate family. Many people wanted to see Theo and pay their respects; however, together, my immediate family and I decided - for a multitude of reasons - we would be the only visitors permitted to enter Theo’s hospital room.
To support others to say a few final words to my brother, I offered blank cards and pens to those who had come to the hospital (see Chapter 2, section 2.2). An accompanying sign read: *Family and friends, thank you for being here and for your love and support. *If you wish to write a note for Tiffany to read at Theo’s bedside, please take a note and envelope and leave it in the basket.* ♥ Theo’s family (Hill, 22/12/2017). The response was overwhelming. On the morning of the day Theo died, I read more than a hundred messages to Theo at his bedside surrounded by my immediate family. These included messages from his best friends, his first and last loves, aunts, uncles, cousins, coworkers, and everyone in between. Some messages read:

- You have taught me to live in the moment.
- Your energy was so contagious.
- You were loyal, trustworthy, real, and vulnerable.
- I’ll always remember how proud of me you were.
- You were there for me when I needed you most.
- I fed off your drive - you made me want to be better than I am.
- You have touched many lives.

(Hill, 1/12/2017; see Appendix A)

Music, dancing, singing, and feasting were a common dominator in most experiences in my life related to my brother. He was the life of the party. *He loved to dance, and he had amazing moves (similar to mine). Dancing is a shared passion for me and my brothers, second only to our shared love of enjoying good food with loved ones* (Hill, 1/12/2017). Later in life, *as part of Theo’s quest to learn to love himself fully, he became passionate about perfecting and caring for his body* (Hill, 1/12/2017) which gave him even more staying power on the dance floor (Hill, 1/12/2017). To honour Theo and his deep love for music, we sang and danced at his
bedside. In a reflection I wrote, it was 20 minutes before we said our final goodbyes and we were literally playing Drake. This is how he would have wanted to leave this world; having us recite the kindest of words and my mom, his mom, singing “is my baby boy listening? I'm rocking you to your paradise” (Hill, 7/12/2017).

**Visiting place.** He left his gym bag on the side of the road in the moments before the accident. In his gym bag was a half a loaf of bread, peanut butter, a key and lock, a compass, his shaving kit, three books... (Hill, 27/11/2017) and other personal belongings. In the time between the day he died and the funeral services, the time I like to call, the in-between (Hill, 29/11/2017), I took the lock found in the gym bag to get engraved. It read, *In Loving Memory Theodore Hill* (Hill, 28/11/2017), and it now resides on the chain link fence covered in love locks in Pier Park in New Westminster, near the neighborhood in which my brothers and I grew up and where we spent a lot of time in the last few years before Theo died.

*Figure 8. Quayside love lock, by J. Urquhart. New Westminster, BC. 2017.*

**Viewing body.** As soon as Theo died in the hospital, my father was adamant that he wanted to view Theo’s body before the funeral; viewing Theo’s embalmed body was part of the
‘in-between’. The day before the funeral, and as part of the beginning of the formal ceremonies that took place the next three days, my immediate family visited the funeral home where he lay. In a journal I reflected, *I walked into the viewing room and there was the beautiful casket I had chosen; a dark mahogany casket. But this time he was in it, or what was left of ‘him’ anyway. I spent about an hour investigating; I took pictures, straightened his tie, and laughed at the way his legs were crossed, so indicative of who he was* (Hill, 5/12/2017).

![Image](image.png)

*Figure 9. The all-star classics, by T. T. Hill. New Westminster, BC. 2017.*

In my final moments of viewing his physical body, I read Theodore the eulogy I had prepared the day before. The next two hours of the viewing included *our family standing around the casket making jokes and crying, sometimes simultaneously* (Hill, 5/12/2017).

*Mourning and celebrating life.* The next day, we held a funeral mass and celebration of life. As a family, we decided on a traditional Catholic mass at the church we knew so well as children. Our cousins and Theo’s godparents participated in the readings and our stepbrother and Theo’s closest friends acted as pallbearers. The choir from the high school my brothers and I attended sang the music and my mother wrote and read a prayer. To close, with Tristan by my
side, I read the eulogy to the crowd of over 500 people (see Hill, 2017). Everyone had a role to play, even the hundreds of people that attended. They witnessed the gathering, they celebrated, they cried, they comforted, and they were comforted (Hill, 6/12/2017). That same evening, the crowd (which seemed to have gotten bigger as the night developed) moved from the church to across the field to the high school my brothers and I attended. The room was filled with flowers, candles, beautiful décor and pictures, dancing, love, laughter, and tears – so many tears (Hill, 6/12/2017). Theo’s favorite local restaurant served endless Lebanese food as we dimmed the lights and watched a slideshow projected on the wall. The slideshow blasted music (see Appendix B) and included photos and videos taken of Theo through the years; honouring his memory and his short life.

**Witnessing cremation.** The next morning was the witness cremation ceremony which was held in a small concrete crematorium. This ceremony was much more intimate, with our immediate family and only six people we invited to join us. There he was again, this time in a wooden box placed on a conveyer belt (Hill, 7/12/2017). We gathered in a circle a few feet away from where my brother lay. I opened the book of *Embers* and recited a poem written by Richard Wagemese (2016). I read:

> IT IS LOVE itself that brings us together.

> This human family we are part of, this singular

> voice that is the accumulation of all voices

> raised together in praise of all Creation, this one

> heartbeat, this one drum, this one immaculate

> love that put us here together so that we could
learn its primary teaching—that love is the energy
of Creation, that it takes love to create love (Wagamese, 2016, p. 46).

My father suddenly, unable to watch the cremation process, fled down the hallway where my stepmother joined him. Moments later the rest of us watched tearfully as the funeral director slowly guided the wooden box, Theo’s body, into the cremation chamber and closed the door. Then, together, my mother and I pushed the red button that activated the fire in the chamber. While this marked the end of the journey with his body in the form I had known it, it was far from being the end of my grief process.

**Rituals.**

*Listening to music.* A few days before the funeral, Tristan and I locked up all of Theo’s belongings into a room in our father’s home. Days after the funeral, as a final goodbye, my immediate family gathered to sort through his belongings. *It felt like an auction. “Here’s his bike, anyone need a bike? Here are his shoes, dad do these fit you?”* I left with a few items, ironically, some of which I coveted from Theo through the years. And here it was, all mine; yet, not given to me so freely and definitely not for the reasons I anticipated (Hill, 10/12/2017). I took his headphones home, the noise-canceling kind. It took a few days before I mustered up the courage to put them over my ears and when I finally did, *I felt him there. And of course it was to music* (Hill, 14/12/2017). I remembered him often listening to music, rereading conversations, looking at photos, watching videos of the funeral (see Hill, 2017), and watching the slideshow played at his celebration of life. I even created my own art to remember him by.

*Tattooing.* Tattooing has always been a way for me to *tell my story; communicate who I am, where I come from, and give tribute to the significant moments in my life and Theo’s death was no different* (Hill, 28/11/2017). Two days after Theo died, *Mom, Dad, Tristan, and I got*
matching tattoos of his echocardiogram, allowing us to keep his heart with us always (Hill, 1/12/2017; see Appendix A). In a journal entry, I wrote when someone asks about it, I get to tell the story about the time my brother died in my arms. How his heart stopped beating and his chest stopped rising. It’s something I’ll never forget (Hill, 28/11/2017).

In the weeks following, I expanded the tattoo to include an anatomical heart, a sword, and jeweled crown. The heart emphasized the experience of him dying. The sword told the story of King Arthur and the legend of his sword, Excalibur; a symbol my brother often spoken of one day getting tattooed on himself. The story is about fate leading Arthur to pull the Excalibur from the stone, permitting him to embrace his identify as a legendary fighter and leader. The crown represented my brother’s deep love for the Fresh Prince of Bel Air; a character from a comedy series who epitomizes humour, style, and swag (anyone thought to carry themselves in a way considered cool). These symbols spoke to who Theo was and worked at becoming.
Weeks after my brother’s death, I created a short story, digital story, and poem to remember Theo and to process and understand my own grief. The short story is found in Chapter 2, section 2.2. The digital story was created by collecting photos, videos, and audio and then layering and ordering them using a video editor program. The footage included moments in the hospital before my brother died, me reading the eulogy at his funeral, photos of us through the years, and audio of his laugh and sounds of a heartbeat and the hospital (see Hill, 2018). As well, I created a poem with a similar method entitled Found (see Appendix C). Creating gave me insight into my relationship with Theo, that I wouldn’t have otherwise developed (Hill, 14/2/2018) and supported a different way of knowing, feeling, and understanding (Hill, 14/2/2018).
**Painting.** Another creative medium I engaged with was painting. My family and I received a letter in the mail from the recipient of my brother’s kidney. It also included words from the recipient’s family members. The letter read:

On November 23rd 2017, at 6:13 pm, the first thought that crossed our minds was gratitude, for sure, but also our hearts and minds were immediately in prayer, for you, feeling your pain and loss. As much as our child and we have been praying for this news, we also knew that a family, who does not know us or our journey, had made the altruistic decision of donating the organs of their loved one to save other lives. (Hill, 21/3/2018)

The letter also offered comfort in knowing that Theo was able to bring hope to so many. In particular, one of his kidneys is nestled in the abdominal cavity of our teenage boy. This kidney was dubbed the SuperDuper Kidney as it has been working for over a month in full capacity! (Hill, 21/3/2018). The letter inspired me to create a painting titled Teenage Boy.

*Figure 12. Teenage boy, by T. T. Hill. Victoria, BC. (Hill, 21/3/2018)*


**Receiving gifts of gratitude.** In addition, I wrote in my final journal entry (of my six months) about the 62 year old father of three wonderful children (Hill, 24/5/2018) who received Theo’s lungs and also sent us a letter with words of gratitude from him and his family. He wrote:

I have always lived a very active outdoor lifestyle which was gradually taken away by my lung disease, idiopathic pulmonary fibrosis. By the time of the transplant in late November my total lung capacity was down to about 30% and declining quickly. I couldn't get across a small room without the aid of oxygen. Needless to say, the new lungs, which are working perfectly, will enable me to return to a healthy, active lifestyle. (Hill, 24/5/2018).

His family (wife, son, and daughters) concluded with well wishes, immense gratitude, and beautiful thoughts, such as: *Please know that every time I see my dad take a deep breath I will think of you* (Hill, 24/5/2018).

**5.2 Reflections**

**Finding comfort.** Ceremonies and rituals were significant in my lived experiences of my brother’s dying and death and my grief because they offered comfort. In a journal entry, I described comfort for me as the *ease of grief... I found it in places that let me honor both his life and his death; a place that held space for sadness, despair, laughter, and joy all at the same time* (Hill, 10/5/2018). For example, I never would have imagined I would dance and sing in the ICU during the dying of a loved one. Yet, *here I was. Holding his battered hand while swaying to his favorite song, tear stained and grinning in the heart of the storm* (Hill, 28/12/2017).
In a similar way, placing the love lock on the chain link fence brought me comfort. *Because he was cremated and not housed in a cemetery, being able to go back and visit him where he lived was so important* (Hill, 27/11/2017), again honoring his life (the place) and his death (the lock).

Finally, holding my brother in my arms as he died, viewing his body before the funeral, and witnessing his cremation provided me comfort in unexpected ways. In those few days, feeling and seeing the physical form of my brother’s body was so incredibly powerful. *The witnessing was for me. I needed to see his body through to the bitter end.* (Hill, 26/2/2018). As a result, early in my grief, I created a painting titled “Embers” (see Figure 7). The painting explored the complexity of fire and its metaphoric relationship with life and death. I wrote, *fire symbolizes light, survival, and life. Stranded and deserted, often we look for fire to keep us alive. Yet, fire also symbolizes devastation and death; the burning and disintegration of a body, leaving only the remains* (Hill, 14/12/2017).
Although comfort was essential for me, it was also important to me to offer comfort to others who cared for my brother. *Albeit these moments weren’t perfect because we all needed different things to grieve, yet alone to feel ease of grief, but it wasn’t for lack of trying.* (Hill, 10/5/2018). For instance, in the hospital, the decision that only immediate family would view Theo in his room was a challenging one to make. There was a balance of honoring my immediate family’s wishes with honoring Theo’s relationships at a time he was unable to make decisions for himself. Therefore, *I offered what I could... an opportunity to say goodbye. A friend of his wrote, ‘I’ve never wrote a goodbye card before.’ When reading this out loud, I then realized, how novel this practice was* (Hill, 22/12/2017).

Funerals, however, are more of a tradition. Theo was not necessarily a religious person, and many of us who decided on the traditional Catholic mass are not either. Yet, there was something about the ritual that was familiar and comforting; *the smell of incense, the formal gathering, the choir singing, the exchange of peace* (Hill, 26/2/2018). My brothers and I were raised Catholic; we attended a Catholic school, participated in Sunday masses, received most of the sacraments, and alter served at funeral services. In a reflection I wrote, *where the funeral took place was not reflective of who Theo was later in his life; however, it did speak to where he came from, where we came from. And in some ways, the mass was simply for the people* (Hill, 26/2/2018). The funeral was a ceremony that offered friends, family, coworkers, clients, and even strangers a place to openly grieve. People could offer condolences to my family and to one another and say a final goodbye to Theo’s closed casket.

**Getting closer.** Engaging with ceremonies and rituals to remember my brother also supported me feeling close to him. Soon after Theo died, I was often asked by people if I dreamt of him or felt his essence or spirit around me. I thought this to be a reasonably challenging
question until the night I tried on his headphones to the song by Gavin James titled the “Book of Love”. And for the first time, since he let go of my hand moments before his heart stopped beating, he was with me. I clutched my chest and closed my eyes to the faint sound of his familiar boisterous laugh (Hill, 14/12/2017). Similarly, on the way to the ferry terminal one evening weeks after Theo died, he showed up in songs. I wrote in a reflection on a painting, it was a beautiful drive along a body of water with the sun slowly setting. I turned on the radio and song after song he spoke to me; this continued even after I changed the station a few times (Hill, 15/1/2018). On the ferry ride home, I created a playlist for him, to Remember Him (see Appendix B), and to remember every time I felt him with me.

Different from music, I painted Teenage Boy to reflect feelings of closeness (literally a short distance away in space) to the physical form of someone I loved so dearly. Although bittersweet, to know his kidney and lungs survived and belong to a teenage boy and father... is unlike any other feeling. A part of him is still out there, near me, close to me (Hill, 24/5/2018). To know that living parts (i.e., his kidneys and lungs) of Theo still exist and live in the physical world, in addition to offering comfort, offered meaning. That is, if my brother had to die, let alone in the way he died, I wrote that at the very least it brought goodness to others (Hill, 21/3/2018).

The process of creating art (such as a poem and digital story) supported me feeling closeness in our relationship and perhaps, understanding our relationship differently, maybe even better (Hill, 14/2/2018). By creating the poem (see Appendix B), I quickly realized that he was ‘I’, and I was ‘you’ (Hill, 14/2/2018). The complexities of who we were to one another resonate in this poem. For instance, segments I used in the poem from his journal identified him as being bold, daring, and fearless, restrained by his mind, and never accountable to anyone but
himself. In his own words to me in old conversations (which are italicized in the poem), I was selfish and self-centred; yet, more important than him and resilient. The process of creating this poem reassured me that it was okay to admit failures and imperfections. And that I didn’t have to romanticize who he was or who we were to one another. We had a complex relationship and we did the best we could with what we had (Hill, 14/2/2018). In the same way, the digital story I created reflected this complexity in our relationship and the complexity of my grief through the contrast of imagery and audio on life and death (see Hill, 2018). Images and video of the hospital were balanced with images of Theo and me as happy, playful children. Sounds of a heartbeat and me singing in the hospital were contrasted with upbeat music and audio of his big beautiful laugh (Hill, 26/2/2018). The process of creating offered me permission to grieve all of what I lost and of equal importance, what I gained.

5.3 Chapter Summary

My second set of findings were identified through my story of my need to remember and my associated reflections. Through my lived experiences, I have been able to identify the importance of ceremony and ritual to grieving and the specific ceremonies and rituals that supported my ability to remember and honour my brother. Ceremonies included one-time activities such as saying goodbye, visiting place, viewing body, mourning and celebrating life, and witnessing cremation while ongoing rituals of remembrance included listening to music, tattooing, creating stories and poetry, painting, and receiving gifts of gratitude. Intentional participation in activities designed to remember my brother while also supporting a continuing bond with him had significant impact on my grieving process.
Chapter 6: My Discussion & Recommendations

*It is an intertwining of science, spirit, and story - old stories and new ones that can be medicine for our broken relationship... pharmacopoeia of healing stories that allow us to imagine a different relationship in which people... are good medicine for each other.*

(Kimmerer, 2013, p. X)

*Figure 144. Braiding sweetgrass, by K. Alexander. Ladner, BC. 2019.*

Al Green - Let’s Stay Together
Chapter 6: My Discussion and Recommendations

My lived experiences of the dying and death of my brother and my grief in the six months following his death have the potential to inform researchers, practitioners, and survivors of a loved one’s death. To support an action-oriented discussion, supported by the criteria of rigor and trustworthiness, this chapter is divided into four sections. Within each section, I summarize key learnings from my own lived experiences and how they support and contrast with existing literature (see Chapter 2, section 2.3). I then identify gaps in literature and/or practice and offer a key recommendation for consideration in both research and practice. Although I present each recommendation on its own, it is important to note that all recommendations are interrelated. All recommendations are driven by my insights and perspectives foremost and supported by literature thereinafter. Furthermore, they are not intended to be prescriptive; instead, they are designed to present opportunities for further exploration and consideration amongst researchers, practitioners, and survivors.

Recommendations include:

1. Practice caution and compassion;
2. Recognize categories and labels as potentially problematic;
3. Offer resources to support goodbyes; and
4. Engage in ceremonies and rituals to support grieving processes.

6.1 Practice Caution and Compassion

Practicing caution and compassion is a theme throughout my autoethnography and is one of the key recommendations I offer.

Discussion. As posited in the literature review (see Chapter 2, section 2.3), rumination (Nolen-Hoeksema, 2001) and obsession about accident details (Armour, 2007) are often
experienced by sibling survivors of motor vehicle accidents. In my case, I reimagined and
replayed the events of the accident that led to my brother’s death, *replaying the narrative I was
given over and over again in my head. Just like a scene in a movie* (Hill, 19/12/2017).
Reimagining the events of the accident was especially challenging for me because of the
inconsistencies with the facts presented to me throughout the process of Theodore’s dying,
death, and my grieving. For example, there was *only a truck, no car. Only a witness, no crowd*
(Hill, 18/12/2017). These inaccurate details of the accident also prompted me to question my
basic assumptions about the good in people (Armour, 2007; Shear et al., 2011) wondering why
bystanders who witnessed the accident did not intervene: *how could people just watch something
like this and be idle to it? How am I supposed to have faith in humanity after this?* (Hill,
15/12/2017). I believe that if I had been provided with consistent, factual, and nuanced
information or if I had been told explicitly that the information being conveyed was emergent
and potentially unreliable, my struggle with the details of my brother’s death and dying would
have been different and less of a struggle; however, it is difficult to ever really know.

My need for facts about my brother’s death and dying is supported in the literature on
sibling bereavement in violent deaths which suggest that sibling survivors who experience
violent, sudden, and unexpected deaths of their siblings are particularly prone to feelings of guilt
(Armour, 2007; Pompili et al., 2013), are often left with unanswered questions (Powell &
Matthys, 2013), and hold vivid memories of how the news of the event was delivered (Armour,
2007). As I expressed in my story (see Chapter 4), I was challenged with feelings of guilt about
not being present when Theo’s accident occurred. This guilt was amplified by not having
answers to questions I had about the accident. Understanding that any violent death may involve
known and unknown facts, and even though I found some answers by visiting the accident site, I
was still left with unanswered questions that included where Theo was going that day, why he jumped in front of the truck, what was he thinking about when he did, and whether or not death was his ultimate goal. Similar to the literature, I also remember clearly how the news of my brother’s accident was conveyed to me. I explicitly remember the news of the event and how it was delivered: *I hear the words brother, at the hospital, in a severe accident, and his identification found near him* (Hill, 1/12/2017).

In general, the research suggests that finding meaning in violent deaths can be extremely difficult. As such, Ryerson (2001) discouraged siblings to seek a coherent storyline of the associated death, and Prigerson and Jacobs (2001) reported that sibling survivors are likely to avoid painful memories. Conversely, I found immense solace when searching for facts and answers, even when facts were withheld, unavailable, or impossible to obtain. Furthermore, rather than avoiding painful memories, I intentionally visited the accident site that led to my brother’s death and, while I was not given all the answers I sought, visiting the site provided me with relief from wondering. The dissonance between my lived experiences and the current body of related research underscores the need for practitioners to be cautious and careful of their often-heavy reliance on research, which may encourage them to assume personal experiences and individual reactions will be similar to existing research and practice guidelines; rather than recognizing both the uniqueness and similarities of one survivor’s experiences to another.

**Recommendation.** My lived experiences as reflected in the story entitled ‘My Need to Know’ (Chapter 4), clearly demonstrate that access to facts related to how a violent death of a sibling occurs can be critical for survivors. This includes not only what information is shared, but how it is shared. In particular, when making information known to survivors, consideration of
the accuracy, clarity, nuance, and consistency of facts is essential, since these aspects of the
telling of information can greatly influence the grieving process of survivors.

Researchers. More research can be done to better understand how to support survivors in
learning facts about how their loved one has been in a life-threatening accident and/or died, in
particular, with traumatic and violent deaths. Studies that can facilitate the opportunity to gather
the lived experiences of survivors learning the events of an accident leading to death can be
better understood to help serve healthcare practitioners who deliver such news. Strong potential
for researchers engaging in patient-oriented action research exists in relation to this
recommendation. Researchers may also translate knowledge learned from studies to support
practitioners in a more practical manner to practice caution and compassion.

Practitioners. Based on my experience, I encourage practitioners such as social workers,
Victim Services workers, police officers, doctors, and nurses to be cautious when sharing
information with survivors. I encourage practitioners to offer information in clear, nuanced, and
transparent ways; and to be honest about what is known and equally honest about what is not
known. Exercising caution is particularly important with regards to the language used to express
facts and details about what happened or what will happen as this can support the grieving
process. Transparency has the potential to decrease the likelihood that survivors develop a false
belief or certainty that they have a full understanding of what happened; in reality, violent deaths
and their surrounding circumstances can be complex and convoluted and facts may be slow to
emerge. I also encourage practitioners to share facts as they are available, treading cautiously
until details are solidified. Once there is a consistent, coherent narrative, a process to effectively
ensure that all practitioners and support services employees (i.e., police, social workers, and
healthcare workers) interacting with the survivor have the same information would be helpful
and supportive to ensure the consistency and accuracy of the information being shared with survivors. Lastly, exercising caution requires that practitioners understand how participants want information delivered (including the details of what happened), recognizing this can change over time. At all times, I strongly urge that information be shared with compassion, where compassion in this context means acting with kindness and empathy, while honouring that every reaction is as unique as the individual experiencing it.

**Survivors.** Survivors are encouraged to treat themselves with kindness and compassion. This means honouring and advocating, when possible, for their own needs. For example, survivors may benefit from feeling empowered to ask for the amount and type of information they want from practitioners. Engaging in a reciprocally kind and compassionate relationship with practitioners will likely be mutually beneficial. Furthermore, survivors will likely be surrounded by other family members and friends who are also grieving so it may be useful to prioritize kindness and compassion when navigating relationships; while recognizing for many this could be challenging, difficult and potentially not possible.

### 6.2 Recognize Categories and Labels as Potentially Problematic

Throughout my brother’s dying and death and my grief, I often found categories and labels to be; therefore, I present this as a recommendation.

**Discussion.** As my lived experiences illustrate, of which are supported in the literature, grief is a multifaceted experience that is not completely captured by a reductionist approach to the process; in other words, grief can involve both negative (i.e., distressing) and positive (i.e., growth) experiences, and this complexity is not always reflected in grief research. This reductionist approach, often considers the negative mental and physical health outcomes (Rostila et al., 2013a, 2013b, 2013c) of grief limiting the ability to recognize that grief reactions and
experiences among sibling survivors span a wide range (Kübler-Ross, 1969), and this focus on the adverse or pathological dimensions of grief can be a detrimental attempt to simplify a complex human experience. Furthermore, trying to reduce grief to a formula or ‘one size fits all’ does a disservice to the uniqueness of each individual case of grieving. Similarly, the pathologizing of grief precludes a consideration of other dimensions of lived experience of grief. This is particularly problematic because of the lost potential of acknowledging and examining these lived experiences in ways that inform what supports sibling survivors. A more nuanced and holistic approach to studying grief recognizes the potential for post-traumatic growth (Tedeschi, 1999), defined as a transformation of “self, philosophy of life, and relationships with others in the aftermath of events that are considered traumatic” (p. 321). Therefore, there are benefits to understanding and researching lived experiences in their entirety.

Just as adopting a pathological stance on grief can be problematic, so too can over using common labels to describe or categorize a type of death. I was faced with challenges in comprehending and accepting (Prigerson and Jacobs, 2001) my brother’s death because of its sudden, unexpected, and violent nature. Although much of the research suggests that as a sibling survivor of suicide I would be struggling with feeling shame, stigmatization (Feigelman, 2009) or even struggling with my self-worth (Mash et al., 2013), I was more worried about the accuracy of the story of what happened to Theo; I wanted to know what was true and not what others thought or assumed about what had happened. With regards to Theo’s accident, I believe that representatives from the Insurance Corporation of BC and the Royal Canadian Mounted Police labeled my brother’s death as a suicide prior to there being conclusive evidence that it was a suicide; this was problematic in my lived experience. Essentially, I struggled with the term ‘suicide’ and had to get the facts of what happened in order to discern in my own mind whether
or not it was suicide. Merriam Webster defines suicide as “the act or an instance of taking one's own life voluntarily and intentionally.” This definition is congruent with what others seemed to understand when they learned of my brother’s death. However, for me, this accepted definition of suicide does not capture the complex circumstances that may have led to the physical act that resulted in my brother’s death. In Theo’s case, these complex circumstances included his belief that he was having a mild psychotic episode (Hill, 29/11/2017) the day before the accident. I will always wonder whether Theo ‘voluntarily and intentionally’ took his life, or if he was suffering from a psychotic break and imagined a completely different reality, or as I describe in my journal, if maybe he thought he was a samurai preparing to slay the dragon. But the truck wasn’t a dragon and he wasn’t a samurai. Or maybe he was? (Hill, 15/12/2017).

**Recommendation.** Through my own lived experiences of my brother’s dying and death and my own grief, I learned that by exclusively focusing on categories (e.g., death by suicide and complicated griever) or assuming a pathological orientation to grief, health practitioners and service providers can inadvertently negatively impact survivors’ grieving processes.

**Researchers.** Recognizing the complexities of death, dying, and grief; more research is needed that explores the idiosyncratic nature of grief and grieving, particularly in the context of sibling bereavement resulting from violent death. Researchers are also invited to unpack and reconsider commonly referenced terms such as complicated grief and suicide. This might include exploring questions related to what participants want known about their grief processes and experiences, instead of asking participants questions that support the over-use of labels and categories and reduce grieving to a uniform process. Additionally, further qualitative research could explore how survivors make sense/understand categories and labels. This might inform a
more nuanced approach to using such labels and to finding more nuanced approaches to supporting survivors using a resilience and strengths-based lens.

**Practitioners.** This recommendation invites healthcare practitioners to support grieving patients in a more holistic manner that extends beyond diagnoses and labels. This is not to suggest that professionals should disregard the use of these labels/concepts; however, it calls for greater consideration of context when applying labels. Practitioners are invited to consider labels’ potential impacts on survivors and of the ways in which these labels may or may not apply; without *proof* of suicide, it may be detrimental to use the label with survivors. Further, it may be helpful to avoid assumptions that loss and grief processes are solely negative. Rather, acknowledge that for each individual there will be unique responses, some of which may actually be positive. Acknowledging both possibilities opens paths for individual survivors to explore post-traumatic growth and resilience-building as a potential outcome of grief. When the focus is on looking for symptoms, assumptions can be made about what actions will be helpful. For example, when considering whether or not someone diagnosed with complicated grief should return to an accident site, a counselor may advise against it based on the diagnosis. However, for people such as myself, visiting the accident site can provide answers to questions and relief from rumination and wondering. Practitioners are encouraged to be aware that labeling can be limiting and stunt the potential for growth as a possible positive outcomes of the death, i.e., newly found personal strength and resilience (Pretorius et al., 2010), recognition of new possibilities (Taku, Tedeschi, & Cann, 2014), and greater sense of meaning in life.

**Everyone.** My recommendation to those who share space with siblings and family members of someone who has died is to be aware that labels such as ‘suicide’ may not always capture the holistic reality of how someone has died. Assumptions can be dangerous and
ultimately influence and shape others’ grief processes. That said, as each experience and reaction is unique, some may actually take comfort in labels and understanding them may aid in their meaning-making processes. Therefore, treading gently around labels and allowing individuals to advocate for how they want to use them in their own grief processes is suggested.

6.3 Offer Resources to Support Goodbyes

The lack of resources to support saying goodbye to my brother is a challenge emphasized in my research; therefore, I recommend fostering spaces for greater understanding of what it means to say goodbye and offering resources to siblings and families when saying goodbye to a loved one. ‘Saying goodbye’ for the purpose of this discussion and recommendation, refers to when siblings and families are given time (and the opportunity) to be with their loved one before their clinical death.

Discussion. As witnessed throughout my own lived experiences of my brother’s dying, there may be value in considering ceremony and rituals not only after a death, but as part of supporting the dying process. Through my lived experiences I have learned that honouring the last moments in my brother’s life at the hospital was an important part of saying goodbye. Not all people will need, want, or even have opportunities to say goodbye; but when feasible, it may be beneficial to have resources on hand that support survivor’s ability to enact ceremonies, rituals and other processes as part of saying goodbye.

Saying an intentional goodbye to a dying loved one is important to many survivors (Heyland et al., 2006). Opportunities for saying goodbye can be particularly useful in situations where stress and anxiety levels are high, like in an ICU setting (Azoulay, Chaize, & Kentish-Barnes, 2014). In the ICU, my anxiety and stress levels were heightened with being given legal responsibility for my brother’s medical care. In the face of my anxiety, stress, and immense
emotional pain, I found some comfort in saying goodbye. In particular it was important to say goodbye to my brother in ways that would have been meaningful to him, like dancing to his favourite songs beside his bed, as well as in facilitating the goodbyes from friends and family members.

Research posits that there are two key needs of family members as they are saying goodbye to loved ones, these include having a comfortable place to say goodbye (Millner, Paskiewicz, & Donald, 2009) and having supportive nursing staff during this process (Andrew, 1998). When Theo was dying, many extended family members and friends visited the hospital and gathered in the hallways and the waiting room to show their support for Theo and our immediate family. Many people wanted to see Theo and pay their respects; however, together, my immediate family and I decided, for a multitude of reasons, we would be the only visitors permitted to enter Theo’s hospital room. I instinctively understood their desires to say goodbyes and so I sought to find a comfortable place and format for those goodbyes (letters written to him to be read at his bedside) to take place. Having a space in a hospital that allows family and loved ones of the dying to enact rituals and processes that bring them comfort is important, particularly in the event of a traumatic or sudden death. For example, I never would have imagined I would dance and sing in the ICU during the dying of a loved one. Yet, here I was. *Holding his battered hand while swaying to his favorite song, tear stained and grinning in the heart of the storm* (Hill, 28/12/2017).

Although comfort was essential, it was also important for me to offer comfort to others who cared for my brother. *Albeit these moments weren’t perfect because we all needed different things to grieve, yet alone to feel ease of grief, but it wasn’t for lack of trying.* (Hill, 10/5/2018). For instance, in the hospital, the decision that only immediate family would view Theo in his
room was a challenging one to make. There was a balance of honoring my immediate family’s wishes while also honoring Theo’s relationships at a time he was unable to make decisions for himself. Therefore, I offered what I could... an opportunity to say goodbye. A friend of his wrote, ‘I’ve never wrote a goodbye card before.’ When reading this out loud, I then realized, how novel this practice was (Hill, 22/12/2017). As demonstrated by my lived experiences, having a space to say goodbye can include making psychological space and time to say goodbye. Creating such time and psychological space can be facilitated, at least in part, by nursing staff.

I was also fortunate to have nursing staff support my family’s goodbye tattoo ritual by offering an image of Theo’s echocardiogram from the moments before his death. Minutes later, the nurse hands us a printed copy of his echocardiogram. Elated, we thank her, and my parents join the conversation about our elaborate plans to get inked (Hill, 1/12/2019). Two days after Theo died, Mom, Dad, Tristan, and I got matching tattoos of his echocardiogram, allowing us to keep his heart with us always (Hill, 1/12/2017; see Appendix A). In a journal entry I wrote, when someone asks about it, I get to tell the story about the time my brother died in my arms. How his heart stopped beating and his chest stopped rising. It’s something I’ll never forget (Hill, 28/11/2017). I will cherish always the opportunities I had to say goodbye to Theo before he died in the same way I will cherish the ceremonies and rituals that honoured him after his death.

Post-death activities are often the focus of literature that explores death ceremonies and rituals. Much is known about practices related to funerals and memorials (Bäckström, 2019; Lobar, Youngblut, & Brooten, 2006); a significant portion of literature around these practices is connected to religion and culture (Lobar et al., 2006). Braun and Nichols (2010) studied death practices of Pacific island groups and reported that Filipino Americans largely incorporate death practices grounded in the Catholic faith. Similarly, my Filipino Canadian family decided to
honour Theo with a Catholic mass, allowing our extended family and friends to come together (Hoy, 2013) to express love and respect for him (Kastenbaum, 2004), and to feel connected (Kastenbaum, 2004). Vale-Taylor (2009) specifically recognized post-funeral rituals that are less connected to specific religions like visiting the grave, revisiting meaningful locations, sharing photos, sharing memories, lighting candles, listening to music, and creating. Many of these types of activities are also relevant to the story shared in Chapter 5. Overall, ceremonies and rituals have the potential to offer those who are bereaved emotional comfort, a sense of belonging, and support in continuing bonds with their loved one who has died (Hoy, 2013; Vale-Taylor, 2009). For these reasons, while in the absence of suggested structures, as a family we improvised to support our goodbye to Theo.

**Recommendation.** My lived experiences of my brother’s dying and death highlighted the need for a deeper understanding of what is needed for goodbyes, as well as, resources to facilitate the goodbyes.

**Researchers.** Due to the lack of literature related to honouring people outside of the religious context as they are dying, more research is needed in this area. In particular, research is needed to gain further insights into what types of non-religious ceremonies, rituals, or activities that siblings and families have enacted to support their time to say goodbye in such a critical time. Conducting this research alongside families who have lost a loved one in the ICU could allow for better understanding of what ceremonies, rituals, or activities best supported their saying goodbye process. This could also create an opening for researchers to learn from families how healthcare practitioners can better support the saying goodbye process.

**Practitioners.** Increased action from hospitals and practitioners to provide additional options to siblings and families in the form of ceremonies and rituals to accompany the death
process. In particular, art and music therapists can be incorporated into their practices to support people in critical conditions. Another consideration is to explore the offering of end-of-life doulas who provide support to families and have a particular specialization in supporting the needs of survivors.

**Survivors.** The death of a sibling can leave survivors overwhelmed with many tasks and decisions related to finances, their siblings’ remains, funerals, and their siblings’ personal possessions. My own lived experiences showed me that, while it is easy to get immersed on all of the difficult planning and decision-making that may need to occur after a death, there is potential value in intentionally honouring their own needs and their sibling by engaging in creative methods of saying goodbye. While practitioners may have suggestions for goodbye practices, it is important that sibling survivors feel empowered to say goodbye in ways that fit for them, their sibling, and their shared relationship. Prior to my brother’s death, I would have found it difficult to imagine that dancing and singing in the ICU around my brother’s body would feel like the right way for me to say goodbye; however, I am grateful that I engaged in those activities because they allowed me to say a very personal goodbye and to feel comfort in knowing I gave my brother the sort of send-off that fit who he was.

6.4 Engage in Ceremonies and Rituals to Support Grieving Processes

As prominently featured in my autoethnography of my brother’s dying and death and my grief, I have found that engaging in ceremonies and rituals supported and continue to support my grieving process. As such, this is the final recommendation that I propose.

**Discussion.** My lived experiences of the dying and death and my grief in the six months following his death support the idea that ceremonies and rituals can be an important part of
grieving processes and can specifically help with the continuity of relational bonds and meaning-making--essential elements of the grieving process.

The limited body of research into sibling loss suggests that the needs and lived experiences of sibling survivors are not well understood in the literature. Particularly in adulthood, the needs of survivors of sibling death have not been identified (Wright, 2017). My relationship with my brother was complex and important, and I had specific needs to stay connected. In particular, I wanted to maintain an ongoing connection with my brother that acknowledged the complexity and importance of our relationship. As such, I engaged in rituals and ceremonies that honoured our relationship before Theo’s death, and our continued bond. As Klass and colleagues suggested, I have benefited from continuing attachment to my deceased loved one in new circumstances (Klass et al., 1996). Some of the comforting rituals with which I engaged are in direct support of literature that endorses that moving on and letting go is not ideal (Neimeyer & Attig, 2001). For example, the ritual of tattooing Theo’s echocardiogram supports not forgetting but embracing his death; it provides a constant reminder of him. Further, some of the rituals and activities I engage in on a regular basis support me in continuing to maintain a connection with Theo and to re-visit some of our experiences, interactions and his passions to help live with loss (Attig, 2001). These rituals also offer a sense of meaning-making or meaning creation.

Neimeyer (2001) identified activities that support people who are bereaved to move forward by integrating the death of a loved one into life as meaning-making. Meaning-making activities can facilitate survivors in coming to terms with reasons for the death (Neimeyer, Burke, Mackay, & van Dyke Stringer, 2010). One of the rituals that supported meaning-making for me, was receiving gifts of gratitude. For example, acknowledgement from the recipients of
my brother’s organs, supported the idea that my brother’s life would have contributed to saving and providing a better quality of life for others. My brother was able to bring hope to so many, in particular, one of his kidneys is nestled in the abdominal cavity of our teenage boy. This kidney was dubbed the SuperDuper Kidney as it has been working for over a month in full capacity! (Hill, 21/3/2018) and another to 62 year old father of three wonderful children (Hill, 24/5/2018) who received Theo’s lungs and also sent us a letter with words of gratitude from him and his family.

In addition, I made sense of the events leading to my brother’s death (Morgan, 1997) by visiting the accident site where I uncovered relief from wondering. Visiting the accident site supported my grieving process by affording me the opportunity to create a new relationship with place. I didn’t need to avoid it anymore. And I didn’t need to understand more about the where (Hill, 16/2/2018). Similarly, placing Theo’s newly engraved gym lock on the chain link fence in a beautiful park by the Fraser River was helpful to me; it gave me another physical place and symbol to visit when I wanted to feel close to him (Hill, 27/11/2017). This activity was part of my meaning-making journey as it allowed me to connect my brother and his death to a place where we had so many shared memories from his lifetime; it was a step towards integrating his death into my new, altered reality (Neimeyer, 2001).

In summary, ceremonies and rituals have the ability to positively impact survivors’ grieving processes by providing comfort and facilitating a continuing bond with their loved ones who have died (Hoy, 2013; Vale-Taylor, 2009). My own lived experiences included ceremonies and rituals that were integral to my grieving process; I received significant comfort from my participation in them. Ceremonies and rituals created physical and mental space to honouring my brother and to allow myself to experience a multitude of complex emotions (Hill, 10/5/2018).
While many of these ceremonies and rituals were undertaken very intentionally for the purposes of providing comfort, I was unprepared for the levels of comfort that I experienced through the rituals and ceremonies that involved Theo’s physical body (Hill, 26/2/2018). This demonstrated for me that there can be benefits from partaking in rituals and ceremonies that are outside my usual comfort zone; therefore, there is value in supporting people and researchers to learn more about the benefits of engaging in all kinds of death-related rituals and ceremonies.

**Recommendation.** This recommendation is applicable to all those who grieve or will grieve in their lifetime and researchers. Specifically, sibling survivors are called to reflect on ceremonies and rituals that honour their experiences with the death of their sibling and their relationships with their sibling. Moreover, this recommendation encourages survivors to engage with rituals and ceremonies that can support continuing bonds with their siblings and make meaning of their deaths. Based on my lived experiences, I posit that engaging with creative expressions such as art, music, and writing may complement and work in conjunction with rituals and ceremonies.

**Researchers.** The current body of grief literature does little to understand the impacts of creating space for ceremonies and rituals throughout the dying process beyond religious death and dying practices. There is an opportunity to understand and explore how ceremonies and rituals of varying types support survivors. Perhaps, there could be value into learning more about what characteristics ceremonies and rituals from a variety of cultures have in common; this could be helpful in developing new ceremonies and rituals that could be useful in a variety of contexts. Specifically, developing a larger body of phenomenological studies that look at the human experience when engaging in rituals and ceremonies have the potential to be valuable.
Practitioners. While many practitioners already focus on support for continuing bonds and meaning-making with ceremonies and rituals, there may be value for practitioners in diversifying their knowledge of various ceremonies and rituals so that they can expose survivors to a broad variety of practices, perhaps increasing the likelihood that survivors will connect with practices that feel more relevant to their individual experiences.

Survivors. In the midst of the dying and death of a loved one, it might feel counterintuitive to focus on ceremonies and rituals. However, survivors are encouraged to be open to engaging with ceremonies and rituals, recognizing that these can involve a vast array of religious, non-religious, and personally developed activities. Survivors may benefit from seeking ways to embed ritual and ceremony into everyday life and to be open to the idea that rituals do not have to be formal or prescriptive. Contrastingly, survivors may benefit from knowing that there is no need to engage in ceremonies and rituals out of obligation if they do not wish to do so.

6.5 Chapter Summary

In chapter 6, I present my discussion and recommendations. My discussion synthesizes my stories with current and relevant literature. My recommendations are presented as practice caution and compassion; recognize categories and labels as potentially problematic; offer resources to support goodbyes; and engage in ceremonies and rituals to support grieving processes. All of which are based on my lived experiences; but cannot be taken as prescriptive ways forward; instead, these recommendations act as guidance to researchers, practitioners, and survivors of a loved one’s death.
Chapter 7: The End of the Beginning

Grief, I've learned, is really just love. It's all the love you want to give but cannot. All of that unspent love gathers up in the corners of your eyes, the lump in your throat, and in that hollow part of your chest. Grief is just love with no place to go.

(Anderson, 2014, para. 8)

Figure 15. Embracing uncertainty, by T. Zialcita. New Westminster, BC. 2017.

Sam Smith - Too Good at Goodbyes
Chapter 7: The End of the Beginning

My autoethnographic study aimed to: explore my lived experiences of the dying and death of my brother and my grief in the six months following his death; reflect on my use of creative arts-based methods (i.e., creative writing, music, poetry, painting, and photography) to shape and guide my grieving process; cultivate an understanding of grief as a process to be honoured as opposed to a problem to mitigate; and inform policies and practices to support siblings who are bereaved. In this chapter, I summarize my stories (i.e., findings) and the recommendations that emerged from the research. I present study outputs, limitations, and significance; and finish with an emphasis on considerations for future inquiry.

7.1 Summary of Stories

The two stories shared in this thesis emerged from my lived experiences and explore my need to know and my need to remember. Both stories explore my experiences and how they impacted my grieving process. My need to know outlines my strong desire for as many concrete details as possible regarding the accident that led to my brother’s death. Ultimately, these factual details contributed to my ability to make meaning of my brother’s death. Reflections on my need to know look at my how learning facts supported me in reimagining the accident, experiencing relief, and learning the limitations of language. My need to remember focused on the ceremonies and rituals that were part of saying goodbye to my brother and remembering him after his death. My story of needing to remember facilitated the identification of how ceremonies and rituals provided me with comfort and the ability to have a continuing bond with him after his death. Reflecting on these two stories and my own learning throughout the writing of this dissertation, I offer recommendations in chapter 8 related to my process.
7.2 Summary of Recommendations

As a result of my lived experiences of the dying and death of my brother and my grief in the six months following his death and relevant literature, I identified four recommendations for consideration by researchers, practitioner, and survivors of a loved one’s death in chapter 6. These include:

1. Practice caution and compassion;
2. Recognize categories and labels as potentially problematic;
3. Offer resources to support goodbyes; and
4. Engage in ceremonies and rituals to support grieving processes.

These recommendations are meant to function as guiding principles and be considered in conjunction with one another. Ultimately, they are intended to facilitate reflective and considerate behaviours that can support researchers, practitioners, and/or survivors.

7.3 Study Outputs

The findings of this research, and my research process more generally, has the potential to inform and support dying, death, and bereavement research, policy, and practice. Specifically, the research methodology, methods, findings, and recommendations will inform the development of articles for the Journal of Death Studies, OMEGA - Journal of Dying and death, and Journal of Creativity in Mental Health; and conference presentations at the Association for Death Education and Counselling (ADEC) Conference and the International Death, Grief, and Bereavement Conference. With an interest to bring the research ‘alive’, I will create less traditional forms of knowledge translation through the adaptation of the research and creative products (e.g., paintings, photographs, poems, music) to be virtually interactive (i.e., website,
audiobook) and showcased at a student exhibit making the research accessible to multiple audiences.

### 7.4 Limitations of Study

Limitations of the study reflect the inherent limitations of qualitative research in its inability for its findings to extend to wider populations with the same degree of certainty that quantitative research can (Creswell, 2014). With only myself as a participant of the research, there will be narratives that are not captured in the findings. My lived experiences of the dying and death of my brother, and my grief are unique and cannot be replicated. My chosen methodology can be criticized with a positivist view as being self-indulgent and unreliable (McKenzie, 2015); however, this orientation to research can be criticized as being overly narrow and prescriptive of what constitutes good research and valid knowledge. To contrast, there is a growing body of literature that focuses on the validity of qualitative research (Cho and Tent, 2006) and proposes that each individual story reflect and offer unique insights into the phenomenology of the human experience (Allen-Collinson and Hockey, 2009). As such, my recommendations are based on my lived experiences, yet designed to be broadly applicable while recognizing that comprehensive generalizations cannot be made. As well, autoethnography can be rigorous while incorporating emotion and creativity (Adams, Holman Jones, & Ellis, 2015; Hockey, 2007). Personal experiences may at times rely on memory as a research tool. To mitigate this, personal accounts were written as events unfolded (i.e., journaling, self-recording) and facts about my brother’s dying and death were checked with friends and family to increase reliability. Finally, although a narrative literature review (Méndez, 2013) was involved in the research; there is an extensive body of literature specific to premature, violent, suicide, and sibling bereavement that can be further explored.
7.5 Significance of Study

Examining my lived experiences of my brother’s dying and death and my grief in the six months following his death has the potential to: support people in navigating and understanding their grief; introduce creative arts-based methods that may offer support for people through their grief; improve bereavement services and support for people who are grieving; inform intensive care unit (ICU) hospital practices; and contribute to theories in dying, death, and bereavement.

The key stakeholders who may benefit from this inquiry include: myself as a grieving individual, researcher, and participant of this research; my mother, my father, my brother, and our extended friends and family; healthcare practitioners (i.e., clinical team members, physicians and nursing staff, counsellors, social workers, and art, music, and play therapists); those who work with people who are grieving or who have or will experience grief and loss; and educators, students, and other scholars interested in researching and teaching sibling bereavement and bereavement more generally.

7.6 Implications for Future Inquiry

It is important to note that my thesis is a strong example of the power of one story. Furthermore, I acknowledge that my single story does not preclude other experiences and does not claim prescriptive actions. Instead, the story of my lived experiences of my brother’s death and dying and my grief may promote further discussion within research and practice. Through one story, insight can be gained; however, this requires an understanding that deeply personal experiences require consideration of individual experiences in conjunction with commonalities that have been identified in larger groups can then be cultivated, and identification of further possibilities for research and practice may emerge. This autoethnography may promote future inquiry that may emerge as a result of its ability to:
1. Illuminate the strong potential for researchers to engage in patient-oriented research that could support a better understanding of how to support survivors in learning facts about how the death of their loved ones, particularly with traumatic and violent deaths.

2. Encourage studies that can facilitate the opportunity to hear the first hand lived experiences of survivors first contact with learning the events of an accident leading to death can aid in translating knowledge learned from studies to better support practitioners who deliver such news.

3. Underscore the need to be cautious around labels. Further research into the best use of labels and benefits and pitfalls of a pathological orientation to grief may be useful.

4. Highlight the lack of literature related to death ceremonies and rituals outside of a religious context. Research is needed to gain further insights into what types of non-religious ceremonies, rituals, or activities that siblings and families have enacted to support their time goodbye in such a critical time.
Chapter 8: My Final Thoughts

*do not skip your struggle.*

*it’s in the dark room,*

*the unknown-the invitation,*

*we develop the tools*

*to find our light.*

(Doby, 2018, p. 3)

*Figure 16. The power of a single story, by K. Goodwin. Victoria, BC. 2018.*

Labrinth - What We Leave Behind
Chapter 8: My Final Thoughts

In this final chapter, I offer brief reflections on my journey of engaging in this research and writing this thesis. In doing so, I explore the inextricable interconnections between my grief and the distinct, yet overlapping roles I held throughout this journey: researcher, participant, and sibling survivor of my brother’s death. Drawing from my own reflections about this process, I conclude my thesis by sharing four significant learnings that my grief and the process of writing my thesis taught me.

When proposing my initial research topic focused on engaging children whose siblings had died, I never imagined that my own brother would die in the midst of the research process. His unexpected death presented me with an opportunity to take a deeper dive into my initially proposed research topic and focus on myself, explicitly exploring my own lived experiences of my brother’s dying and death and my grief in the six months following his death. My bold choice to explore this topic at such an early stage of grief was, at times, challenging, but it also offered me a unique opportunity to simultaneously navigate the intertwining roles of a researcher, a participant, and a sibling who is bereaved. Through the process of writing this thesis, studying myself, grieving, and navigating my own grieving process, I discovered four essential learnings: (1) self care is fundamental; (2) grief is messy; (3) process is the point; and (4) sharing is liberating.

8.1 Self Care is Fundamental

When I chose to embark on this challenging and deeply personal research, it was of the utmost importance to identify what my personal needs, wellbeing and self-care strategies would be before, during, and after the research. The ethics process supported me in identifying and articulating what my needs were as a researcher, as a participant, and as a sibling survivor. As
self care can look, feel, and sound different for everyone, it was imperative that my health as a participant was the primary priority as I reflected on the ethical considerations of my thesis.

As a proactive measure, I journaled, used art as a tool to process, and leaned on a group of people who offered support. I wrote in a journal, *with the string of losses and with me still feeling stuck in something so surreal* (Hill, 2/1/2018), I made the decision to commit to seeing a professional counsellor throughout the entirety of my journey. As such, I was given structured time and space to grieve; a sacred space that was mine to do whatever I needed regardless of where I was in the mess of it all. *It was there, even if I didn’t need it to be. The consistency and reliability was important* (Hill, 4/1/2018). *Seeing my counsellor was not about ‘fixing’ anything, I didn’t need her to tell me how to grieve* (Hill, 4/1/2018). What I needed was validation and accountability. *I needed to know that there was no wrong way to grieve such a complex loss* (Hill, 4/1/2018) her support most often came in the form of holding me accountable to my needs, to practicing self-care, and prioritizing my holistic wellbeing; she also continuously reminded me that my needs as a researcher, participant, and sibling survivor had to remain at the forefront of my process. In addition to these elements, a few months before I was to end my thesis, I took an extended medical leave. This took the form of a six-month hiatus to give myself more time to process what the end of my thesis really meant and to allow the vital element of self-care to occur naturally, in its own time.

8.2 Grief is Messy

Grief sometimes gets better then worse, then better, then worse; there are ups and downs. What I learned through my research process is that grief does not flow in a straight line, and it does not follow a linear process of timelines, schedules, requirements, and procedures. My grief took on its own agenda, showing up full force in the most unexpected of times. This, at times,
presented challenges while I was operating within the confines of a research process where I needed to meet deadlines and important commitments. I learned that these unexpected and sometimes unwelcomed waves of uncontrolled grief were richly informative to me as a researcher, to me as a participant, and to me as a sibling who is bereaved. I learned that my grief was messy and that being immersed in grief’s mess has a lot to teach me - should I accept the invitation no matter the inconvenience. It is often said that everyone grieves differently; it may look or feel different depending on who is experiencing it, how a death or dying occurs, and on a range of other factors. But what I never knew until I gained this lived experience of being a researcher, participant, and sibling survivor, is that there is no wrong way to grieve. Throughout this process, I gave myself permission to grieve in the ways and times I needed to, no matter what that looked like.

8.3 Process is the Point

Shortly into my research, I learned firsthand that arts-based processes and significantly more valuable than the resulting pieces of art. The process of creating, moving, building, and reflecting was of greater service to me as a researcher, as a participant, and as a sibling who is bereaved over the final product. For example, as an early Christmas present, a friend bought me paint and canvases which prompted me to immediately immerse my grieving process in art. I wrote, *painting has a way of keeping me in the moment. My breath slows and a sense of calm washes over me* (Hill, 14/12/2017). Ironically, while I painted to escape my reality, I painted about my reality. In a journal entry I wrote, *sometimes it was creating art to simply escape, and other times it was to paint to understand an element of my experience more deeply* (Hill, 23/3/2018). While painting, I reflected on the evolution of what was being painted as it related to my lived experiences of my brother’s dying and death and my grief. Several paintings were
inspired by a specific experience, and others were prompted by a reflection on a given experience. And when painting wasn’t an option, I journaled... and journaled... and sometimes I journaled about journaling (Hill, 23/12/2017). Journaling was my outlet, it’s where my overwhelming emotions are stored when they became too big for me to hold (Hill, 23/12/2017).

Writing a thesis while navigating the complexities of grieving was a challenge, but the process of creating supported me in continuing; it did not matter what the outcome was to be - it was the ability to keep learning, keep writing, and keep moving that mattered. That said, it was essential that my research would be reflective of the level of care and love I had for my lived experience; however, the process of conducting the research is what impacted me most as a researcher, a participant and, a sister who is bereaved. The research process for my thesis has instilled in me a strong belief in the power of arts-based methods because of my deeply personal and multifaceted experience with it.

8.4 Sharing is Liberating

Most people experience a loved one’s death; therefore, most people experience grief. Sharing my story is one way of honouring Theo and, ultimately, of honouring myself. Preparing my thesis as an autoethnography on the dying and death of my brother and the grief six months following provided ongoing opportunities to speak openly about his dying, his death, and my process in many arenas. This has been a result of my story being integrated into my ‘work’ as opposed to an experience from which I needed to just move on. Consequently, I was privileged to share in moving conversations, exchange stories, meet new people, and reconnect with old friends. I was afforded opportunities to present to large classes and conferences, showcase my photography, and partake in intimate conversations. I learned that sharing grief is crucial and I
learned to seek spaces in which to share, feel it, process it, and witness it. I learned that grief is a powerful shared experience and an inevitable part of being human; sharing it generates power, creates community, and promotes growth and wisdom.
FROM OUR VERY first breath, we are in relationship.

With that indrawn draft of air, we become joined to everything

that ever was, is and ever will be.

When exhale, we forge that relationship by virtue of the act of living.

Our breath commingles with all breath, and we are a part of everything.

That's the simple fact of things.

We are born into a state of relationship, and our ceremonies and rituals are guides

to lead us deeper into that relationship with all things.

Big lesson? Relationships never end; they just change.

In believing that lies the freedom to carry compassion, empathy, love, kindness

and respect into and through whatever changes.

We are made more by that practice.

(Wagamese, 2016, p. 44)
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Appendix A: Eulogy

Why we are here

Almost a year ago today, my brother, Theo, texted me to say that when he became a portfolio manager, he would fly me in for weekends from my new home in Victoria. This was after I told him it was too bad I was moving away when we had just started getting closer as adult siblings. He told me, and I quote, “there is a time and a place for everything.” I know I am not alone in feeling that now is not the time for this. Like so many of you here today, I remain shocked, devastated, and feel cheated that we have lost you so soon.

My name is Tiffany Hill and I am Theodore’s younger sister. In times of terrible tragedy, it can be helpful to look for the light and humour. And one thing that brings a smile to my face is the glee that I know Theo will feel watching me publicly praise and affirm him. So today is about honouring you, Theodore. My brother, a son, a friend, a cousin, a banker, a dreamer, and a thinker of beautiful complex thoughts and philosophies.

In his 33 years, Theo shared much laughter and many good times with his family and friends. He loved music and dancing and believed in enjoying the finer things in life. His big smile and gregarious laugh endeared him to so many.

Theodore was, as his Tinder profile states, a refined gentleman with monocle and top hat included. His interests included: philosophy, economics, fitness, and art.

Philosophy and learning

While Theo openly disliked the structure of traditional education, he absolutely loved learning (just one example of Theo’s paradoxical nature). As a 12 year old, he spent days reading and rereading each volume of the Childcraft Encyclopedia set our mother bought him. He feverishly read countless sci-fi and fantasy novels holed up in his room. Though he claimed to have no time for university, he frequently borrowed (without asking) my philosophy textbooks. Then, without warning, he would quote Plato and want to discuss the Allegory of the Cave. He would follow those conversations up by sending me YouTube videos to watch about quantum science. This, from a guy who credited our mom with him finishing high school, claiming he wouldn’t have done it if she didn’t drive him to night school regularly. But I will remember you as always thinking, always learning, always arguing, I mean debating…

Economics

In recent years, Theo began working towards becoming a certified financial advisor, channeling his love of learning into a formal structure and becoming a self-proclaimed “library hermit.” After ten years of a successful career with TD bank, where he built strong, long standing, positive relationships with clients, he wanted concrete proof that he could master the craft of investing. Theo was absolutely fascinated with the way that currency functions in our society and the world. He devoured those finance books the way he did those encyclopaedias when he was 12. He wanted to perfect his understanding of money.
Fitness

As part of Theo’s quest to learn to love himself fully, he became passionate about perfecting and caring for his body. Crossfit, eating organic chicken, and exercising were outlets for his desire to be focused, disciplined, and follow a routine.

Art

Becoming super fit meant Theo had even more staying power on the dance floor. Theo loved to dance, and he had amazing moves (similar to mine). Dancing is a shared passion for me and my brothers, second only to our shared love of enjoying good food with loved ones, which makes attending family weddings some of our best shared memories.

His qualities

When Theo was into something, he was all in - obsessive some might say. This was as evident in the way he played video games as it was in the way he read about investing later in life. During his teenage years, he used to get in trouble all of the time with ‘those guys’, dye his hair different shades of blue, red, and yellow tips and wear his signature white visor and pacifier to raves. It was during this time that my mom took a trip to LA and left Theo in charge of groceries and meals for himself, me, and our younger brother, Tristan. That entire week we ate instant noodles, allowing Theo to spend the bulk of the grocery money on video games! While some would say that was irresponsible, Theo would say that it was all in the name of training to be the best gamer he could be. The training paid off and after Grand Theft Auto 4 was released, he was ranked top 100 in the world out of hundreds of thousands of players.

Speaking of obsessions, Theo liked to say he would meet a girl, be attracted to her, and then accidentally fall in love. Over the years he become wiser, and said he had to remind himself that “liking three songs in common does not make her your soulmate”. While he had plenty of crushes over the years and loved to horrify me with inappropriate stories, he was fortunate enough to know love. The kind of love that shapes lives and is never forgotten. The kind of love that gives you glimpses of the best you can be.

Theodore once said, “I've always strived for perfection - mastery - in whatever I’m fancying at the time.” When I was child, he got his black belt in karate. This was the only sport he fancied consistently and didn’t quit. This had some pretty painful implications for Tristan and me because we were the people he practiced on. And he was really good at it. Theo didn’t care that we were younger and untrained, he reveled in his victories all the same.

Theo loved competition, almost as much as he loved winning. This made him the worst to play board games with. He would brag endlessly about beating Tristan and me in our 8 hour Risk sessions. Eventually, Tristan and I learned to form an alliance, allowing us to occasionally beat Theo, which he hated. Six or seven years ago I casually mentioned my impressive typing speed of 130 words per minute. The competition was on and for years after he would insist we have typing races on side by side computers. He never beat me. You can only imagine how disappointed he was recently when I didn’t know my IQ when he wanted to compare it to the impressive score he received when he took a test online.
Others’ perspectives

How incredibly surreal the last two weeks have been. Such sadness, grief, and most importantly, laughter. In Theo’s final moments, we read him goodbye letters written by friends and family at his bedside, held his hand close and heart closer, reminisced his rebellion, and danced to and sang some of his favourite songs. Reading the goodbye letters was a gift to all of us. Some words from those who loved him include:

You have taught me to live in the moment
Your energy was so contagious
You were loyal, trustworthy, real, and vulnerable
I’ll always remember how proud of me you were.
You were there for me when I needed you most.
I fed off your drive - you made me want to be better than I am
You have touched many lives.

His human flaws, how we can honour him, and ending

Like all of us, Theo wasn’t perfect. He had struggles with which he truly suffered. These vulnerabilities were some of the reasons he tried so hard to find routines that allowed him to be healthy and to focus on positive goals. For that, I am so incredibly proud of him.

Moving forward, Theo would want our family to support our mom, who he loved so dearly and felt so connected to. On life, Theo wrote that he wanted to “Let it naturally occur, trust in the process and be kind to yourself. Be curious.” He would want us to always be aware of the weight our words have with others who may be struggling.

Among his many accomplishments, I think it's safe to say that the top two happened moments before and after his death. After 17 years, he forced our family back together in the most intimate and vulnerable way. And finally, always the hero, he gave the gift of life to the four recipients of his liver, lungs, and kidneys. To commemorate Theo, Mom, Dad, Tristan, and I got matching tattoos of his echocardiogram, allowing us to keep his heart with us always.

A person is the sum of the people they spend their time with. Theo wrote, “I choose to surround myself with the thoughts and words of the greatest people who have ever lived.” So thank you to you all for being a part of who Theo was.

I love you big brother. Rest easy my fresh prince. And I'll be seeing you.
Appendix B: Remembering Him Playlist

This playlist is a collection of songs curated as a means to express my relationship with Theo, my lived experiences of his dying and death, and my grief. The songs are reflective of the dynamic and multi-dimensional aspects of human relationships, life, death and grief; uniquely weaving differing genres, tempos, artists and stories. Click here to download the playlist.

<table>
<thead>
<tr>
<th>Title</th>
<th>Artist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Broken Halos</td>
<td>Chris Stapleton</td>
</tr>
<tr>
<td>Family business</td>
<td>Kanye West</td>
</tr>
<tr>
<td>Follow me</td>
<td>Jasmine Thompson</td>
</tr>
<tr>
<td>Giving up ground</td>
<td>Chelsea Cutler</td>
</tr>
<tr>
<td>God’s plan</td>
<td>Drake</td>
</tr>
<tr>
<td>Growing pains</td>
<td>Ludacris &amp; Fate Wilson</td>
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<tr>
<td>Hallelujah</td>
<td>Pentatonix</td>
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<tr>
<td>Heavy</td>
<td>Birdtalker</td>
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<tr>
<td>Hold on, we’re going home</td>
<td>Drake</td>
</tr>
<tr>
<td>I’ll be missing you</td>
<td>Diddy &amp; Faith Evans ft. 112</td>
</tr>
<tr>
<td>Jealous</td>
<td>Labrinth</td>
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<tr>
<td>Just the same</td>
<td>Bruno Major</td>
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<tr>
<td>Let’s stay together</td>
<td>Al Green</td>
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<tr>
<td>Moon river</td>
<td>Frank Ocean</td>
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<tr>
<td>Not gonna let you walk away</td>
<td>LOLO</td>
</tr>
<tr>
<td>Palace</td>
<td>Sam Smith</td>
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<tr>
<td>Passionfruit</td>
<td>Drake</td>
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<tr>
<td>See you again</td>
<td>Wiz Khalifa ft. Charlie Puth</td>
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<tr>
<td>Started from the bottom</td>
<td>Drake</td>
</tr>
<tr>
<td>Supermarket flowers</td>
<td>Ed Sheeran</td>
</tr>
<tr>
<td>The book of love</td>
<td>Gavin James</td>
</tr>
<tr>
<td>Too good at goodbyes</td>
<td>Sam Smith</td>
</tr>
<tr>
<td>What we leave behind</td>
<td>Labrinth</td>
</tr>
</tbody>
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Appendix C: Found Poem

I’ve found this
that we are here to live our lives
so well that Death will tremble
to take us.

that I am bold, daring,
fearless, and
free to renew myself
to forge art and form truth.

that I can’t do it alone –
achieve goodness
or perfect stillness
while restrained by my mind.

that the world is a cruel dark place
so I take what I can
get high to forget – wondering
how the hell I ended up here

not accountable to anyone
but myself.

And I’ve found this
that you’ll be more important than me
lead a fulfilling life
with iteration, resilience,

and an eye for opportunity
and pivotal moments.

that you are selfish, self-centred,
and scared shitless of
saving a world
that hardly thinks of you in return.

So congratulations.

I love you, well...
the closest thing to love I know.

th

(Hill, 13/2/2018)
Appendix D: Consent Form

Dear ____________,

You are aware that I am currently working towards my Master of Arts in Interdisciplinary Studies at Royal Roads University and that writing a thesis is a requirement to graduate from this program. I intend to write on the topic of my lived experience of my brother, Theodore’s, dying and death, and my grief.

In order to explore this topic, I am engaging in autoethnographic research which will involve exploring my personal experience of grieving, reflecting on my process, and relating it to scholarly literature. I intend to use my own journal and other writings, paintings, photographs, and poems as part of my research process.

As I explore my grief process and my brother’s dying and death, I will mention immediate or extended family, friends, and healthcare practitioners, and that may include you. I will only mention you by your first name with your permission, but there is a possibility that you may be able to be identified due to the circumstances or the relationship I describe in my research. For example, I may mention “my mother” or I may mention “my family” as a whole, of which you may be a part. Therefore, you may be identified because of our relationship. Since this thesis may be available online after completion, it may be possible that you could be identified by those who read it.

*It is important to note* that what is written in my thesis is from my perspective and not a representation of your thoughts, words, or experiences.

I would like to know if you are comfortable with possibly being mentioned by your first name in my research. If you are not, please indicate below, and I will not mention you by name. Rather, when I need to refer to you I will use terms like “my mother” or “the social worker” or another term that you feel is most appropriate to describe you. Also, if you wish to withdraw your consent for me to use your name at any time, you may do so without any negative consequences. Lastly, if you do not want to be mentioned in the research, this too will not result in any negative consequences.

When I have completed a final draft of my thesis, I will offer to provide you with a copy to review in order to ensure that you are comfortable with what I have written about you. I encourage you to offer feedback, thoughts, and concerns you may have.

Warmest regards,
Tiffany
I agree to being mentioned by my first name in this research.

Agree  Disagree

Another term (if applicable)________________________

Date__________________ Name__________________ Signature__________________

I agree to being discussed in this research.

Agree  Disagree

Date__________________ Name__________________ Signature__________________