Remembering Michael Stone:

# Crafting Digital Testimonies of Grief from the Opioid Overdose Crisis

Aaron Michael Goodman

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By: Aaron Michael Goodman

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	Dr. Angela Failler	External Examiner
	Dr. Gada Mahrouse	External to Program
	Dr. Steven High	Examiner
	Prof. Tim Schwab	Examiner
	Dr. Yasmin Jiwani	Thesis Supervisor
Approved by	Dr. Jeremy Stolow, Graduate Pro	gram Director
March 25, 20	19 Dr. Andre Roy, Dean Faculty of Arts and Science	ce

## ABSTRACT

Remembering Michael Stone: Crafting Digital Testimonies of Grief from the Opioid Overdose Crisis

Aaron Michael Goodman, Ph.D. Concordia University, 2019

An opioid overdose crisis is spreading across North America. In 2017, over 4,000 people experienced drug-related deaths in Canada. The highest number of fatal overdoses have occurred in British Columbia (B.C.), where in 2017, the Coroner's Service reported over 1,400 fatalities linked to drugs. This was a significant increase from 985 overdose deaths in 2016, 518 in 2015, and 369 in 2014.

Photojournalists and documentary photographers are drawing attention to the situation, but many of their images reflect a longstanding tradition of problematic and stigmatizing visual reporting. In many photographs, people who use drugs, and increasingly individuals who experience overdoses, are portrayed as exotic and dangerous social outcasts. Visual narratives of this nature also fail to communicate that people from all sectors of society are being affected by the crisis.

In July 2017, B.C.-based meditation and yoga instructor, writer, and activist Michael Stone, died from an opioid overdose. It was later revealed he suffered from bipolar disorder. Over the year following Michael's death, I collaborated with his wife, Carina Stone, and two of his closest friends and meditation students, Rose Riccio and Andréa de Keijzer. Inspired by participatory methodologies developed by oral historians and certain documentary filmmakers with the National Film Board (NFB) of Canada, I assisted my interlocutors in recording nuanced and personal audio testimonies about their memories of Michael, their ongoing connections to him, and their experiences of grief. Together with my collaborators, we produced a digital memorial titled *Losing Michael* using Klynt as a non-linear platform.

I was particularly interested in experimenting with oral historian Henry Greenspan's method of collaborative testimony, which he describes as "learning together" (2010a, p. xii) and "knowing with" (2010a, p. 230), as well as the narrative approach and continuing bonds theory

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from counselling psychology. I also used autoethnography in order to explore how my mother's mental illness, prolonged disappearance in my youth, and death have impacted me. Reflecting on these personal experiences allowed me to assist my interlocutors in creating their narratives with a sense of compassion.

The purpose of this project is to resist dominant narratives about the opioid crisis and individuals who have experienced drug-related overdoses. The intention is also to help create awareness about the ramifications of these deaths for decedents' loved ones and communities. Simultaneously, the project aims to highlight how many individuals who use drugs and experience overdoses suffer from mental health issues, and that there is a need for more early intervention programs for vulnerable people. *Losing Michael* can be accessed at the following URL: www.losingmichael.com

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I humbly dedicate this project to all the families and friends of people who have lost their lives to drug-related overdoses.

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## PREFACE

# **GOODBYE AGAIN**

I was the only one in the hospice room with my mom. It was July 2015, and she had been in a deep sleep for days, waking up for only brief spells. Each time she opened her eyes, I pressed damp cloths to her forehead, trying to bring down her burning fever. In the fleeting moments when she was conscious, I fed her ice chips from a teaspoon, hoping that if she stayed hydrated, somehow, she would live a little bit longer.

I had months to prepare for her final descent toward death. I was with her at St. Paul's Hospital in Vancouver when a doctor told her that she had pancreatic cancer, and she would not live for more than six months. That was in February. Not long after that, she moved from her apartment overlooking English Bay to hospice in the Shaughnessy neighbourhood. By mid-summer, she was rail thin, and we knew the end was coming soon.

My mother was a watercolour artist. She painted snow-covered fields, trees, antique barns, and flowers of all kinds. When I was a boy, I stood in the doorway of her small studio at the back of our home in Ottawa watching her paint at a wooden table. She mixed colours on porcelain palettes, and rinsed sable brushes in yogurt containers filled with water. I was welcome in her silent and creative space, and I marvelled at all that she brought to life on paper.

After she moved to hospice, I covered the walls of her room there with her paintings. I placed one of her largest, a lily in bloom, over her bed. Over the weeks that followed, I watched her slip in and out of consciousness, and I prepared myself to say goodbye for the last time. The author of "The Tibetan Book of Living and Dying," Sogyal Rinpoche (2017), writes that as a witness to someone's dying, the most important thing is not to cling. I *wanted* to let her go freely, but part of me felt that I would never be ready.

It was close to 10:00 p.m. on a Sunday in July, and I pulled my chair close to my mom's bed. I held her hand, closed my eyes, and listened to her soft rattling breath. Suddenly, she sounded like she was choking. I ran into the hallway looking for a nurse, but there was no one in sight. I returned to my mother's room. Her quiet breath had resumed, and I regained my sense of calm. I reminded myself: 'She's dying. That's why we're here.'

My mind drifted to a time when I was in the fifth grade, and the fire alarm at my school sounded. It was weeks after my mother had disappeared. She was suffering from bipolar

disorder, and had been in and out of hospital. The psychiatric ward was like a prison, and she did not want to be medicated, so she fled. As the fire alarm rang, I raced for the stairs with the children in my class. We inched our way down the cramped stairwell like a pack, our bodies close together. I felt the need to move faster, to get out of the building quicker. I began to shout, releasing some of the anger and confusion that had built up in me since my mother had vanished. I remember the kids' faces as they turned to look at me. They were clearly more afraid of me than a potential fire. When I think of that moment, I see that I was also not overly disturbed by the fire alarm. I was terrified of having to survive without my mom.

For the next 15 years, throughout my youth, and as I grew into an adult, she was missing. All that time, my mother was moving from place to place across Canada, determined not to be found. She called a few times, but gripped with paranoia, she refused to tell me her whereabouts.

I was not aware, but over the course of a few years, she had been building a thriving art gallery in Saskatoon. When I was 14, she got in touch, and I flew there to see her for a couple of days. I watched as she taught dozens of adults and children to paint. They sat at fold-up tables that she placed in the centre of the gallery. My mother walked slowly behind them, glancing over their shoulders, offering tips about holding brushes, creating the impression of shadows, and getting the proportions of their images just right. One afternoon, we blazed through the countryside under a vast summer sky. She let me drive down a washboard road, and as the van picked up speed, began rattling and veering off course, she pleaded with me to slow down. I wanted to tell her the same thing. After all, she had been running out of control for years.

In spite of all that she had created in terms of her gallery and community of students, I sensed that none of it would last. She told me that she was being poisoned by the dry cleaner's two doors down from her gallery in the same shopping mall. And before long, she left everything that she had built in Saskatchewan, and vanished once again.

When I was in my early twenties and an undergraduate student, she finally got the medical care she needed. She moved to Vancouver where I was living, and over time, we tried to rebuild our fractured relationship, but it was never easy.

Years later, as I sat with my mother in hospice, I wished her dying would go on forever. Her breath trailed off into silence. Although she was leaving, and this time for good, in that moment, I felt like we had never been closer.

#### **INTRODUCTION**

#### **Introducing Michael Stone**

In the early morning of July 13, 2017, Michael Stone left his home in B.C.'s Gulf Islands and boarded a ferry to the nearby city of Victoria. The sun had not yet risen. Carina, his partner of seven years, and their two children, both under four, were still asleep. Later that morning, Michael telephoned Carina from Victoria and said he planned to get his hair cut, do a workout, and run some errands before making his way home. Prior to ending the call, he asked Carina to call him later on to check on him. He said he was not feeling well.

When evening came, Michael had not returned, and had stopped answering his phone. Naturally, Carina became concerned and called BC Ferries to ask if he had boarded a return vessel. They said they had not seen Michael, but told her not to worry, and that they would keep an eye out for him. Hours after putting her kids to sleep, Carina, who was expecting her third child with Michael, looked out her living room window and saw someone walking up the path to their home, flashlight in hand. She says she knew right away that it was the police and the news would not be good.

When Carina opened the door, an RCMP officer told her that Michael had been found unconscious in his blue pickup truck in Victoria, and had been taken to the city's Royal Jubilee Hospital. The officer accompanied Carina by police boat to Victoria, and she was driven to the hospital where Michael was on life support. She stayed at his bedside for two days. In a last act of goodwill, Michael's kidneys and lungs were removed for donation, helping to save three people's lives, and he passed away. Toxicology reports later indicated that Michael had consumed opioids, including the powerful and synthetic drug, fentanyl.

Michael was 42-years-old, an innovative meditation and yoga instructor, a socially conscious thinker, writer, and was loved and respected by many people around the world. In the days following his death, several journalism organizations, including the *Victoria Times Colonist* (2018), the *Vancouver Sun* (Meissner, 2017), *Globe and Mail* (Woo, 2017), and CBC (Schmunk, 2017) reported on his death. Some journalists indicated that Michael had founded a meditation and yoga centre in Toronto known as the Centre of Gravity, and that he had led retreats in North America and Europe. Many also revealed that Michael had suffered from bipolar disorder, something only a few people who were close to him had known.

As a journalist and communication studies scholar with a longstanding commitment to collaboratively producing counter-narratives about the opioid crisis with people who use drugs, and as someone with an interest in yoga and meditation, I had concerns about the nature of the media coverage of Michael's death. It struck me that his overdose received considerable attention from journalism organizations, primarily because he was a public figure. In emphasizing the circumstances of his death, I concurred with Katherine Kline, a psychotherapist who knew Michael and is a friend of Carina's. She stated in their reporting on Michael's passing, news organizations accentuated the "drama of a fallen guru" (personal communication, July 29, 2019). Not only was he a well-known spiritual teacher, but as a white, middle-class man, he fit the standards of 'normalcy.' Although photojournalists frequently capture images of people who have experienced overdoses, media organizations rarely produce write-ups about individuals who die as a result of consuming drugs, unless they are deemed to hold noteworthy positions in society.

The lives of all people who pass away from causes related to drug use are important, but Michael's death reflected the urgency of the public health crisis to me in particular manner. In the days following his passing, I kept thinking to myself: 'If a yoga teacher, someone who dedicates their life to being healthy, can die after using drugs, we are all vulnerable to experiencing a similar fate.' I had not met Michael in person, and since most of the journalism articles about him were relatively short and limited in scope, I longed to know more about him. Beyond learning about the cause of his death, I was interested in knowing how he had lived, and how people who were intimately and closely connected to him were experiencing his passing.

A few weeks after Michael's death, Carina and two of Michael's closest friends, Rose Riccio and Erin Robinsong, published a personal article about him in *Lion's Roar* (Sperry, 2017), the website of the Buddhist magazines *Lion's Roar* and *Buddhadharma*. They wrote and shared their piece in order to provide a fuller picture of Michael, and to fill some of the gaps in the reporting by dominant journalism organizations. The women confirmed that Michael had lived with bipolar disorder since his youth, and that he received an official diagnosis in 2015. They indicated that he was preparing to publicly disclose his mental illness, but added that stigma about the condition had kept him from taking that step. They wrote that he had experimented with a range of treatments, including psychiatric medication, but like many people with bipolar disorder, he continued to struggle with the symptoms of the condition. Carina, Rose,

and Erin wrote: "He seemed unshakeable and capable of holding everyone else's suffering. And he did, but he struggled with his own" (Sperry, 2017, para. 4).

The women explained that on the day Michael experienced his fatal overdose, he had contacted a pharmacy that serves people who are affected by substance use issues. Carina, Rose, and Erin added that he may have requested a "safe, controlled drug to self-medicate" (Sperry, 2017, para. 11), but was told that he was not eligible to receive medication from the pharmacy. They indicated that he then bought opioids on the street that likely contained the fentanyl that led to his death.

Learning more about how Michael suffered from bipolar disorder and reading the women's piece left me wanting to hear even more about him from individuals who knew and cared about him. Although I have not been personally impacted by the opioid crisis, I know the pain of having a loved one with a mental illness, as I note in the preface. My mother did not use drugs, and she did not die from an overdose, but her bipolar disorder shaped my life in fundamental ways.

When journalists report on fatal drug-related overdoses, they rarely follow up and cover how these deaths impact decedents' loved ones and communities. In the days after Michael's passing, I thought about Carina, whom I also had not met, and considered how Michael's death will inevitably impact her and her family. She will have to care for her children without her partner, and their kids will have to grow up without their father. I also thought about Michael's students and friends who had lost a gifted and devoted mentor and guide. And I thought about Michael. He had written four books on yoga, meditation and parenting, and was about to publish his fifth. He also produced a podcast called Awake in the World and offered a number of online meditation courses. His death meant that he was unable to continue making the contributions he was capable of, and as such, his passing is a loss for us all. Michael is by no means the only one whose life has been cut short as a result of an overdose. The public health crisis is growing, and although governments across the country insist they are responding appropriately, more needs to be done to ensure that individuals with mental illness and other vulnerable people are not at risk. Although thousands of other individuals have lost their lives after using drugs, given my personal history in relation to my mother's mental illness and death, I felt motivated to collaborate with people who were affected by Michael's passing.

#### The opioid overdose crisis and harm reduction

Nearly 4,000 people died from drug-related overdoses in 2017 in Canada (CBC Radio, 2018). B.C. has seen the highest number of overdoses in the country. Every day, more than four people die in the province after consuming illicit drugs (The Canadian Press, 2018). In 2017, B.C.'s Coroner's Service reported over 1,400 deaths attributed to drugs. This marks a significant increase from 985 in 2016, 518 in 2015 and 369 in 2014 (Lupick, 2018). Journalism organizations have primarily focused on the situation in Vancouver's Downtown Eastside (DTES). Meanwhile, the rate of overdose deaths is increasing most rapidly in urban centres outside of Vancouver, including Victoria and Surrey (Lupick, 2017a). In the U.S., more people under 50 are dying from drug-related overdoses than any other cause (Katz, 2017), including motor vehicle accidents and gun violence (Durkin, 2018). Opioid overdoses are claiming lives at a faster rate than HIV/AIDS did at its peak in 1995 (Lopez & Frostenson, 2017).

In 2011, it was believed that 60,000 to 90,000 people in Canada were affected by opioid addiction (University of British Columbia Public Affairs, 2011). A rapid influx of fentanyl and carfentanil on the market starting in the mid-2010s has made the situation more critical. Fentanyl is a synthetic opioid and part of the same class of drugs as heroin, morphine, and oxycodone (Johnson, 2016). It is imported from China, produced in illegal labs in Canada, and it is widely available on the streets. The drug is as much as 100 times more potent than morphine (Howlette, Giovanetti, Vanderklippe, & Perreaux, 2017), and an amount as small as a grain of sand can kill someone if consumed (Johnson, 2016). Carfentanil, also commonly sold on the streets, is used as an elephant tranquilizer and is 100 times stronger than fentanyl. People who ingest less than 20 micrograms, or amounts smaller than a grain of rice, can die (Larsen, 2016).

Many people who consume illicit street drugs contaminated with fentanyl first become addicted to opioid pain medications such as OxyContin that are widely provided by physicians and healthcare providers in North America (WBUR, 2015). Over the last decade, the number of people who have been prescribed opioid medication has grown exponentially. Canada and the U.S. now have the highest rates of prescription opioid use in the world (Gomes, et al., 2014). In the U.S., more than 72,000 people experienced fatal overdoses in 2017 (Ingraham, 2018). According to the Centers for Disease Control and Prevention, almost two-thirds of these individuals had consumed prescription or illicit opioids (2018).

As the number of people impacted by the crisis surges, harm reduction researchers and advocates are calling on authorities to allow more overdose prevention sites (OPS) and

supervised injection sites (SIS). OPS and SIS are spaces where people can inject heroin and sometimes consume oral and intranasal drugs in supervised environments. They can access clean needles and other harm reduction materials. Some sites also allow people who use drugs to test substances for fentanyl (Ramlakhan, 2018).

In May 2017, Canada's federal government confirmed its support for the creation of two OPS in Surrey, one in Vancouver, and a mobile consumption site in Montreal (The Canadian Press, 2018b). A month later, Health Canada approved three OPS in Toronto. Meanwhile, in August 2018, Ontario's newly-elected Conservative government led by premier Doug Ford announced it was delaying the approval of OPS (Ramlakhan, 2018). In response, a group of harm reduction advocates began operating an OPS in Toronto in violation of the law (Giovanetti & Hauen, 2018). On October 22, 2018, authorities in Ontario announced that the 19 existing OPS in the province need to apply funding from the government in order to continue operating (Dubinski, 2018). Federal Health Minister Ginette Petitpas Taylor has stated that she will inform the Ontario government about the scientific evidence that OPS "save lives" and urge it to keep them open (Hayes, 2018).

#### Photography and the opioid crisis

As the overdose epidemic intensifies, it is important to consider not only how policy makers are responding to the situation, but also how journalism organizations are covering the crisis. Reporters are helping to raise awareness about the situation, and some have produced indepth, well-researched work in a range of media that is helping to inform the public and decision makers about the roots, impacts, and potential solutions to the crisis. Some of these sources include books such as *Dopesick: Dealers, Doctors, and the Drug Company that Addicted America* by Beth Macy (2018), *Pain Killer: An Empire of Deceit and the Origin of America's Opioid Epidemic* by Barry Meier (2003, 2018), and *Dreamland: The True Tale of America's Opiate Epidemic* by Sam Quinones (2015). A noteworthy and community-based podcast about the opioid crisis is titled *Crackdown*, and is produced by Garth Mullins, Alexander Kim, and Lisa Hale (2019).

Michael Shaw argues that some photographers are creating "softer" and "drastically different" images compared to "those used to characterize heroin use in the 1970s, crack cocaine in the late 1980s, and the drug problem plaguing America's people of color and urban poor today" (2017). He claims that many images of the opioid crisis focus on "treatment and

recovery" as opposed to violence and crime. Shaw points to images of white women and men taking part in demonstrations and holding photos of loved ones who have died from drug-related overdoses in, and a woman in recovery cradling her new baby. He also refers to photographs of physicians teaching people how to use Naloxone, commonly known as Narcan, the drug that is used to reverse opioid overdoses, and others. Julia Rendleman is a documentary photographer based in Virginia who is producing an in-depth project about the opioid crisis. Her series, titled *Sisterhood of Recovery* (2018), focuses on women who are imprisoned and participating in an innovative recovery program. Her photographs feature women holding hands and supporting each other in a circle formation, a woman caring for her grandchild because the child's mother is in custody, another woman who is incarcerated embracing her young son, and others.

As sensitive and humanizing as these images are, I view Rendleman's work as an exception. Many of the images that photographers continue to produce about the opioid crisis are problematic. Photojournalists documenting the crisis frequently reproduce tropes established by documentary photographers such as Larry Clark and Eugene Richards, who began producing images of people who use injection drugs in disparaging ways in the 1960s and 70s.<sup>1</sup> According to Gabrielle Hick, these images form a "visual lexicon" that includes recurring "visual mechanics . . . composition, recurrent symbols, and the larger motifs of the visual landscape of addiction" (2017, p. 6). She adds that photographers must understand these conventions in order to counter them and represent people who use drugs and experience overdoses in ways that do not perpetuate stereotypes, stigma, and discrimination.

John Fitzgerald argues that photographers often portray people who use heroin as residents of "dark, seedy, secret worlds." He adds this can "Other the subject, or make them appear different through eroticizing or exoticising them" (2002, p. 374). Stuart Hall asserts that by representing subjects in stigmatizing ways, photographers can engage in "symbolic violence" that can "mark, assign and classify" people. He claims this can amount to "ritualized expulsion"

<sup>&</sup>lt;sup>1</sup> Photography that depicted people who use drugs in stigmatizing ways became particularly common in the 1960s and 1970s, partly because cameras became widely accessible for the first time. According to Gabrielle Hick, there are earlier examples of problematic photography focused on individuals who use drugs, particularly after the passing of the Harrison Narcotics Act in 1914 (USA), the law that taxed and regulated opiate and coca leaf products. Hick states there was a concentrated effort to stigmatize people who used drugs, including in photography, at that time. She adds there are also examples of denigrating cartoons and drawings of people who use drugs that date as far back as the 1800s (personal communication, Oct. 26, 2018).

(1997, p. 259). I see this playing out in the way that many contemporary photographers represent people who use drugs and experience overdoses as sick, dirty, and as threats to society.

Certain photos of people who use drugs produced by documentary photographers have taken on iconic statuses. These include some of Clark's images of teenagers experimenting with sex and drugs published in his 1971 book, *Tulsa*, and his collection of photos, *Teenage Lust* (1983). Clark was addicted to drugs and insists that his photos are not exploitative. However, critics such as Ken Johnson claim that his approach leads viewers to experience "moral queasiness" and that his work is "transgressive." Johnson explains: "Seduced into looking, you become complicit in what feels like a creepy voyeurism" (2005, para 10). The cover of Eugene Richard's 1994 book, *Cocaine True, Cocaine Blue,* features a close-up photograph of a woman clenching a syringe in her mouth. In recent years, many journalism organizations have also published images of individuals who use drugs with syringes in their mouths. Although photographs like this may be visually compelling to some, they perpetuate the impression that people who use drugs are deranged, primitive, and should be feared. Some of photographers who have replicated this trope include James Nachtwey (2018), one of the world's most celebrated conflict photographers, and Malcolm Linton (2005), a photographer who works with Polaris Images, an international photography agency based in New York.

In recent years, as the opioid crisis has spread, there has been a spike in the number of photojournalism images published in print and online publications of individuals who have experienced overdoses. These people are often pictured collapsed in public spaces, typically as emergency workers attend to them. On January 18, 2017, CBC News published a photograph that is fairly typical of others that journalism organizations have disseminated about the opioid crisis, along with a text-based article, titled *Fentanyl crisis: Drug overdoses claim unprecedented 922 lives in B.C. in 2016* (Johnson, 2018). The image features a man stretched on his back in what looks like an alley in Vancouver's DTES. His shirt is pulled up and his belly and chest are exposed. Rescue workers wearing purple gloves crouch beside him and hold a plastic mask over his face. The caption reads: "Vancouver firefighters Jason Lynch and Jay Jakubec try to revive an addict who has already had two doses of Narcan after overdosing on fentanyl in Vancouver's Downtown Eastside" (Johnson, 2018). Photographs like this of unconscious people who have experienced overdoses are being widely circulated online, and they affect public attitudes and memory about the crisis. They suggest that people who use drugs and individuals who overdose are social outcasts who lack agency and should only be touched with protective gloves.

Harm reduction researchers and advocates have called on reporters and others to refrain from using stigmatizing words such as "addict." Instead, they encourage people to use language such as "people with substance use disorder." Certain journalism organizations, including the *Associated Press*, have complied and even promoted these requests (Szalavitz, 2017), but many media groups, including CBC, continue to frequently ignore these suggestions.

When it comes to photographers who are documenting the situation, many insist that they are acting with integrity. They may not be willing to consider how the images that they produce about people who are impacted by the opioid crisis may be harmful. For example, Nachtwey insists that he approaches his subjects with empathy:

The worst thing is to feel that as a photographer I'm benefiting from someone else's tragedy. This idea haunts me. It's something I have to reckon with every day, because I know that if I ever allow genuine compassion to be overtaken by personal ambition, I will have sold my soul. The only way I can justify my role is to have respect for the other person's predicament. The extent to which I do that is the extent to which I become accepted by the other and to that extent I can accept myself. (qtd. in Frei, 2001)

In spite of his assertions, Nachtwey's series of photographs of people who use drugs, published by *Time* in March 2018, exoticizes and others these individuals. His images feature people injecting drugs into their arms and necks in outdoor spaces strewn with syringes, huddling under trucks, crouching next to snowbanks, and seeking shelter in restaurant washrooms. He frames individuals being arrested at gunpoint and handcuffed by police, appearing in courts and jails, as well as overdosing and being revived by first responders. The response to Nachtwey's series has been largely positive.<sup>2</sup> However, some people have created pointed memes in response to the images.<sup>3</sup> Others have posted critical comments online.<sup>4</sup>

<sup>&</sup>lt;sup>2</sup> For example, Richard Dalton wrote on Nachtwey's Facebook page: "Though you were a silent witness, your images shout at us from the rooftops. A heartbreaking story that needs to be told, and we need to make sure that this is not the final chapter" (n.d.). Nicole Taylor posted the following message in the same place online: "Real and raw. Painful beautiful work" (n.d.).

<sup>&</sup>lt;sup>3</sup> Albiesaurous Rexpark posted a digitally manipulated image on his Facebook page of the *Time* magazine cover of Nachtwey's *Opioid Diaries* series (n.d.). The edited version features the word "POOR-NOGRAPHY" in red capital letters over Nachtwey's close-up image of a man injecting a needle into his forearm.

<sup>&</sup>lt;sup>4</sup> Alison Webb posted the following statement on Nachtwey's Facebook page about his image of a man collapsed on his back with his arms outstretched as a police officer looks down at him: "I find this photo very disturbing, not because of the content of the photos but because you are focusing only on the very worst aspects of the lives of people with severe substance use disorder (addiction). Photos like this only serve to reinforce our cultural

Stephen Meyes, executive director of the Tim Hetherington Trust, writes that Nachtwey framed "homelessness and criminality as being inextricably intertwined with opioid use" (2018, para 11). Vox Visuals Editor, Kainaz Amaria, claims it is alarming that a photographer with as much influence as Nachtwey did not appear to hesitate to share images of this nature with a wide audience. She adds this is disconcerting, because his photographs have the potential to affect the "public and historical record" (Giordano, 2018).

Organizations such as the National Press Photographers Association (NPPA) have created ethical codes for photojournalists. The NPPA emphasizes the need to "avoid stereotyping individuals and groups," to "treat all subjects with respect and dignity," and to "give special consideration to vulnerable subjects and compassion to victims of crime or tragedy" (n.d.). In spite of the existence of codes and language like this, many journalism organizations continue to publish sensational and dehumanizing images of people who use drugs and experience overdoses. As Meyes argues, these photographs largely fail to communicate that people from all sectors of society, and not only street-involved residents of neighbourhoods such as the DTES, long known for its open drug market, are experiencing opioid overdoses (2018, para 11).<sup>5</sup> Photographers documenting the crisis have yet to find effective ways of communicating to publics that vulnerable people like Michael who struggle with mental illness are dying from causes connected to drug use.

Photographers often to try mimic the aesthetic strategies of commercially successful photojournalists such as Nachtwey, whose images are widely recognized. Meanwhile, Sarah Pink argues that photographers are capable of developing alternative strategies (2013, p. 27). So far, however, there seems to have been little critical reflection and innovation among photographers who are documenting the opioid crisis, and many of their images continue to be problematic.

The motivation to capture compelling images can be strong for photographers. Gotthold Lessing claims that in painting, a "single moment of action" must be "the most pregnant one, the most suggestive of what has gone before and what is to follow" (1880, p. 92). Henri Cartier-Bresson, a founder of the Magnum photography agency, coined the term "the decisive moment." It has been described as "the exact fraction of a second when the most artful or interesting of

stereotypes and do not create hope for individuals or families. Most people with substance use disorder recover. How about a photo essay of recovery?" (n.d.)

<sup>&</sup>lt;sup>5</sup> According to the Coroners Service of B.C., 88 percent of people who experienced fatal overdoses between January 1 and July 31, 2018 were found indoors. Just 11.3 percent of fatal overdoses occurred in vehicles, sidewalks, streets or parks, and beyond (2018).

what passes in front of the camera's lens is caught on film" (Kozloff, Levitov, & Goldfield, 2002, p. 5). The expression has influenced the way that many photojournalists have approached their work. While some have interpreted it as encouragement to produce thought-provoking images, it has led some photographers to adopt exploitative practices. Susan Sontag challenges the concept of the decisive moment and the argument that photographs can be taken in a spontaneous way. She argues that images always reflect photographers' personal feelings and biases. Sontag insists that photographers always have choices about how they represent their subjects. In her view, nothing is coincidental. In light of this, she describes photography as a predatory act. She claims: "To photograph people is to violate them, by seeing them as they never see themselves, by having knowledge of them they can never have; it turns people into objects that can be symbolically possessed" (1977, p. 14-15). Unfortunately, this is occurring in the context of the opioid crisis, as photographers chronically victimize vulnerable people.

Bresson emphasized the need for photographers to act ethically. Challenging the way that some photographers have understood the decisive moment ethos, he argues: "One must always take photos with the greatest respect for subject and for oneself" (1999, p. 13). This is critical when one considers, that visual journalism has the power to influence public and cultural memory (Zelizer, 2004).

Images published by journalism organizations are not objective representations of the opioid crisis, nor have some become iconic by chance. Andrew Mendelson (2001) claims that viewers recognize and recall images that they are accustomed to seeing. People are used to viewing photographs of the opioid crisis and of individuals who experience overdoses. The public easily recognizes images of this nature, because many of these photographs are similar to others that have been previously published. Dana Cloud (2004) echoes Sontag and insists that journalism organizations are not neutral, and that the images they publish reflect their attitudes as well as dominant societal values. Larry David Smith adds that journalism organizations do not publish neutral images but produce "stylized interpretations that follow narrative patterns" (1992). Andrea Miller and Shearon Roberts (2010) insist that viewers are receptive to objectifying images and do not oppose the messages they convey, because similar photos are published so frequently, and because of the status that journalism organizations hold in society. Researchers have also argued that the more emotion (Newhagen & Reeves, 1992; Christianson & Loftus, 1987) and anger that images elicit, the more viewers will remember them. In a general

sense, photographs that heighten emotions increase journalism's power to influence perception (Newhagen, 1998).

Scholars have long established that media organizations influence which issues citizens consider the most important in society (Iyengar & Kinder, 1987; McCombs & Shaw, 1972; Gross & Aday, 2003). Furthermore, visual reporting that is negative can affect the way individuals think about issues (Lang, 1991; Lang & Friestad, 1993; Arpan et al., 2006). For example, researchers found that the visual memories people had about the attacks of September 11, 2001 led them to feel elevated levels of anxiety about the possibility of further terrorist incidents (Fahmy et al., 2006). Similarly, photojournalism images about the opioid crisis have the potential to influence public and policy makers' attitudes.

Since journalism organizations rarely produce images that humanize people who use drugs and experience overdoses, it is hard to not view the prevailing model of photography and the tropes that are being consistently reproduced as a form of social control. The more that people who use drugs and overdose are represented in stigmatizing ways, the less likely it is that decision makers will do what is incumbent upon them to ensure that sufficient harm reduction and healthcare programs are in place. It is therefore imperative that journalism organizations and photographers work towards cultivating a "new landscape of addiction" (Hick, 2017, p. 38). Until then, media scholars such as myself have an obligation to draw attention to the problematic nature of much of the visual journalism focused on the crisis and help raise awareness about alternative strategies that could facilitate the production of humanizing counter-narratives.

### Images produced by non-professional photographers

Many troubling images of people who have overdosed have been taken and shared online by individuals who do not earn their livelihoods taking photographs. Since so many people carry smartphones equipped with cameras, non-professional photographers are able to readily produce images of overdoses that take place in public spaces (Hick, 2017, p. 47). One of the most widely circulated and disturbing images of the crisis was taken on September 8, 2016 by a police officer in East Liverpool, OH. It features a man and a woman who had overdosed and fallen unconscious in the front seats of a car. In the image, a boy can be seen in the backseat of the vehicle, and he looks directly at the camera. After police posted the photo on Facebook, it went viral. *VICE News* staff writer Alison Tierney suggests that images like this encourage people to "gawk" and "support stereotypes [that] we as a society have about people who are addicted to drugs" (2016, para 2). Meanwhile, the city's police chief, John Lane, defended the image, stating: "People need to know what is happening. This picture is graphic, it's disturbing. I need people to get upset and help us take back the streets" (qtd. in Jackman, 2016).

The question that must be asked is "take back the streets" from whom? For Lane, the answer appears to be people who use drugs and individuals who experience overdoses. Rather than addressing root causes, Lane prefers to blame those who have died. Like many communities across North America, East Liverpool has experienced a dramatic rise in the number of drug-related deaths. Although many overdoses are connected to heroin and fentanyl use, as noted previously, most people who are addicted to opioids began taking prescription pain medication such as OxyContin<sup>6</sup> (National Academies of Sciences, Engineering, and Medicine, 2017). The Center for Disease Control and Prevention (CDC) reports that individuals who are "addicted to prescription painkillers are 40 times more likely to be addicted to heroin" (cited in Brooks, 2017). Between 2000 and 2016, the number of drug-related overdoses in the U.S. rose by 137 percent. Deaths attributed to opioid pain medication and heroin also jumped by 200 percent (Rudd et al., 2016). An estimated 2.5 million people in the U.S. currently have opioid use disorder (El-Bassel, 2018). Lane is surely aware of these issues, but it is easier to denigrate vulnerable people who use drugs than to publicly denounce government policy and powerful pharmaceutical companies.

In Canada, the number of daily doses of opioid pain medication dispensed between 2012 and 2016 dropped from 238 million to 226 million, although the number of overdoses attributed to opioids rose during the same period. Additionally, the number of overall opioid prescriptions increased from 20.2 million to 21.5 million during the same timeframe (Canadian Institute for Health Information, 2018). Dr. David Juurlink, head of clinical pharmacology and toxicology at Sunnybrook Health Sciences Centre in Toronto, claims that pharmaceutical companies misinformed physicians about the addictive nature of drugs such as OxyContin and often financially compensated them for prescribing opioid pain medication (cited in Ubelacker, 2017),

<sup>&</sup>lt;sup>6</sup> OxyContin was first made available to doctors to prescribe to patients in the mid-1990s. Its manufacturer, Purdue Pharma, launched a campaign aimed at convincing physicians that the drug was an effective medication for people experiencing pain and that it had limited side effects (Lopez, 2018). Since then, Purdue has made billions in profits as doctors have prescribed the drug to countless athletes with minor injuries, people recovering from surgery and dental procedures, individuals with arthritis, and others. In 2014, pharmacies in the U.S. dispensed 245 million prescriptions for opioid pain medication (Volkow, & McLellan, 2016). By that same year, experts say OxyContin was being abused more than any other prescription medication (Van Zee, 2009).

para 4).<sup>7</sup> Juurlink insists that doctors in Canada must limit the amount of opioids they prescribe and find alternative methods of treating people with pain due to the urgency of the fentanyl crisis (cited in Ubelacker, 2017, para. 6).

#### Silencing survivors of the opioid overdose crisis

It is important to consider how dominant journalism organizations report on the opioid crisis, because their work has consequences for individuals who must contend with their loved ones' overdoses. When people die from causes connected to drug use, their family members and friends often experience a mix of guilt, shame, self-blame, isolation, fear, anxiety, grief, and stigma (Feigelman, 2012; Feigelman, Jordan & Bernard, 2011). The widespread production and dissemination of stigmatizing images of people who use drugs and experience overdoses is likely contributing to these difficult feelings. Experiencing these emotions frequently leads individuals who are connected to deceased people to refrain from sharing information about how they died in obituaries and other public spaces, according to Ann Livingston, co-founder of the Vancouver Area Network of Drug Users (personal communication, March 7, 2017).

Yet, as the opioid overdose epidemic intensifies, more bereaved people are beginning to share stories about drug-related overdoses in obituaries (Seelye, 2015).<sup>8</sup> This is helping to challenge the stigma directed against people who have experienced overdoses in dominant media narratives. Some people are using social media in order to share their stories about losing family members and friends to overdoses. For example, when Sherri Kent's 22-year-old son, Michael Kent, experienced a suspected fentanyl overdose in the washroom of a store in Kelowna, B.C., she (2017) posted a photo on Facebook of herself lying next to him in hospital before he died. A number of journalism organizations published the image and a message that Sherri shared online:

I've lost my son to this horrible tragedy and want to make parents aware that it can happen to anyone who decides to touch anything that can be snorted up your nose.

<sup>&</sup>lt;sup>7</sup> For example, Dr. Brian Goldman (2012), a well-known emergency physician and pain expert at Toronto's Mount Sinai Hospital who also hosts the CBC Radio program *White Coat, Black Art,* has indicated that he received financial compensation from Purdue Pharma for advising physicians to readily prescribe drugs such as Oxycontin to people with chronic pain not related to cancer.

<sup>&</sup>lt;sup>8</sup> When celebrities and well-known people have died from overdoses, journalism organizations have traditionally published the causes of their deaths in obituaries. For example, after actor Seymour Hoffman died of a heroin overdose on February 3, 2014, the *New York Times* published an article on the same day and attributed his death to "an apparent drug overdose" and indicated it had been "confirmed by the police" (Weber, 2014).

Fentanol [sic] is the number #1 killer in Canada and it's taking our children and loved ones. Please share this with your family and friends to help prevent another tragedy. (2017)

The fact that certain journalism organizations published this content suggests that some are taking steps to humanize the crisis and those who are affected by it. At the same time, sharing other people's social media posts is a relatively simple tactic. Taking steps to produce more balanced and less sensational photographs about people who use drugs and experience overdoses would be more helpful. However, doing the latter would first require that journalism organizations acknowledge that there are problems with their current reporting practices.

#### Complicating the story by creating a digital memorial

For two years, I studied a range of scholarly areas in my doctoral studies at Concordia University. These included Holocaust testimony, participatory documentary, interactive documentary, memory studies, the representation of natural death and dying in documentary film and video, and more. Fueled by my concerns about the nature of a lot of photography focused on the opioid crisis, I wanted to apply the knowledge that I acquired in my studies by assisting people in producing counter-narratives about the crisis. As noted previously, when I learned about Michael's death, the sadness I felt about it, and my thoughts about the media coverage of his passing, led me to want to work with Carina and Michael's friends.

In late July 2017, I reached out to Carina for the first time on Facebook, briefly introduced myself, and offered my condolences. I indicated that I was interested in potentially working with her to build upon the *Lion's Roar* (Sperry, 2017) piece that she had co-written in order to create further narratives about Michael. I indicated that the form of the work could potentially be a digital memorial. Carina responded quickly, thanked me, and said that she needed to consider the invitation. I recognized that it was a sensitive time for her and I was not expecting a fast response, but within a week she sent me a message and expressed her interest in collaborating with me. I was delighted and asked if she would be willing to also connect me with two friends or students of Michael's who might be open to participating in the project. Shortly thereafter, Carina introduced me by email to Rose, with whom she had written the *Lion's Roar* piece (Sperry, 2017), and Andréa de Keijzer. Rose and Andréa had studied meditation with Michael for years and were among his closest friends. Rose works as a yoga instructor and

massage therapist, and leads Buddhist meditation retreats. Andréa is a performance, photography, and video artist based in Mexico and Montreal. We discussed the project in online calls, and they both agreed to take part in the study.

This project is the culmination of my doctoral research and reflects my longstanding commitment to exploring the opioid crisis as a researcher, journalist, and photographer. The project is autoethnographic in the sense that my personal experiences connected to my mother's bipolar disorder, disappearance, and passing also contributed to my desire to collaborate with my interlocutors. Although I aimed to assist them in recording their memories about Michael and their experiences with grief, as Ellis writes, I "connect the autobiographical and personal to the cultural, social, and political" (2004, Preface, para. 49).

The work also employs research-creation as a methodology. It consists of an interactive digital memorial, audio-recorded testimonies, and images, all created with the study's participants. Although I conceived of the initial idea for the project, it was designed so that I would work collaboratively with my interlocutors from start to finish. Early on, I anticipated that adopting participatory methods would allow us to produce unique and relevant knowledge. The digital memorial includes a brief written component in which I outline the steps that my collaborators and I took, the purpose of the project, and the wider context of the opioid overdose crisis. In this written thesis, I engage with scholarly texts focused on autoethnography, researchcreation, and shared authority in oral history. I explore literature on participatory and activist documentary, digital memorials, and counter-memorialization, which involves remembering people and events in ways that challenge dominant narratives. I also examine sources focused on standpoint theory, witnessing, reflexive anthropology, collaborative testimony, as well as the narrative approach and continuing bonds theory from counselling psychology. These approaches allow interviewers to invite bereaved people to shape stories about loss and grief, and examine their ongoing connections with loved ones who have died. One of the aims of the thesis is to articulate how I worked with my collaborators, as I do in Chapters 2 to 6, so that others can reproduce our methodologies. In Chapter 5, I draw on field notes that I wrote about the process in order to share it with readers.

The research question that is central to this project asks is how can producing personal narratives and a digital memorial about Michael in collaborative ways allow the participants and me to disrupt hegemonic representations of the opioid overdose crisis and individuals who die from drug-related overdoses? Through their testimonies, my interlocutors portray Michael in

nuanced and humanizing ways. They remember him in a manner that is akin to how he lived — with authenticity, dignity, and sensitivity. In their recordings, Carina, Rose, and Andréa reflect on Michael as a caring and loving partner, father, and a wise, committed, and generous teacher.<sup>9</sup> At the same time, they do not portray him in an idealized way, but as a complex person, like every one of us. They also share personal details about their experiences of grief since his passing. In producing, archiving, and disseminating their narratives, my interlocutors and I are incorporating their experiences and voices in the wider discourse about the situation. This is noteworthy, because media organizations have traditionally left little space for representing how people with family members and friends of those who experience fatal overdoses are affected over a long-term period. My collaborators and I are interested in effecting change through the project, namely to urge decision makers to create more early intervention programs for people with mental illness. If the work helps to inform publics and decision makers about Michael, and encourages people to consider the value of making more harm reduction services available to vulnerable people in order to prevent further overdoses, we will be satisfied with that outcome.

Although my three collaborators know each other well and are close friends, they worked on a one-on-one basis with me to create their testimonies and the digital memorial. The women only listened to each other's audio-recordings and became aware of the content of their respective testimonies once the digital memorial was complete and about to be published online. Yet, people who visit the digital memorial and listen to their recordings will come away with a blended experience in their minds. It is through weaving, juxtaposing, and connecting different elements of the participants' individual testimonies that new public memories will be formed.

The digital memorial that I have created with my collaborators focuses on Michael and their experiences of grief following his passing. Our intention is to humanize deaths that result from substance use, and particularly from opioid consumption. Hence, the counter-memorial that we have constructed is different than other counter-memorials that tend to focus on a significant numbers of deaths that have occurred at more or less the same time, such as in the attacks of September 11<sup>th</sup>, and in the terrorist attacks in Paris in November 2015 in which more than 130 people died. Additionally, what sets *Losing Michael* apart from most counter-memorials is the fact that ours is not institutionally driven. It is an individual remembrance made possible through

<sup>&</sup>lt;sup>9</sup> Joan Halifax is a Buddhist Zen priest, teacher, writer, and founder of the Upaya Zen Center in New Mexico. She says: "Seeing the truth of another person's challenges, difficulties, trauma is really important, but at the same time, it is important to also look into their gold, so to speak. To see, you know, wow, this person somehow made it through a war. What were the qualities that made it possible for her to survive?" (qtd. in Salzberg 2018)

collaborative efforts. Lastly, our counter-memorial is different from all others that I am familiar with that commemorate individuals who have died from opioid overdoses, because it uses a mix of media and platforms — emphasizing both audio testimonies and photographic images in an interactive space.

#### Situating myself: Background and social location

#### Examining my privilege and Michael's

The intention behind creating a digital memorial about Michael is to rupture the shame and taboo that surrounds the death of a white, middle-class male, and challenge the framing of deaths such as his as being blamed on individual failures or deficiencies. Michael was known for his knowledge of ancient spiritual traditions, along with his intelligence, kindness, communication, and leadership skills. In spite of these traits, he often suffered behind the scenes as a result of his mental health challenges. By focusing on Michael's passing, which came about after he ingested synthetic opioids, the goal is to create greater awareness about the deeper issue of mental health that often leads individuals, across race, gender, sexuality, and ability, to turn to drugs in an effort to counter the physical and psychosocial pain they experience.

Although I did not anticipate it at the outset of the project, examining Michael's life, the person he was, my collaborators' memories of him, as well as their grief in response to his death, led me to ethnographically explore my personal experiences related to my mother's bipolar disorder, prolonged disappearance in my youth, passing, and my own grief. I am intimately aware that by personalizing Michael and myself in this project, I risk losing the political significance of the issue, namely, its social impact and implications for the health of the public, and many who are affected by this health crisis. Like Michael, I recognize that as a middle-class white male, I have a degree of privilege in the society in which I live. By highlighting elements of Michael's life and my own, I understand that I am overlooking, at least in this project, many others who use drugs or have experienced opioid overdoses and have been racialized or deviantized in dominant media and even political discourse. I recognize there is a paradox with this initiative. By personalizing Michael and attempting to make him grievable, at the same time, I am removing him from the wider context where drug use is mapped onto a class and race-based system. Robin DiAngelo argues that white people are not educated to recognize their privilege North American society, which has been built upon institutionalized racism (2011, p. 56). She

refers to Peggy McIntosh (1988), who insists that "whites are taught to see their perspectives as objective and representative of reality" (cited in DiAngelo, 2011, p. 59). I am not under the illusion that Michael's or my experiences as white, middle-class men, are representative of all others, particularly those of racialized individuals, LGBTQ people, women, individuals with physical or mental health challenges, and people who experience chronic economic deprivation, and homelessness. At the same time, I believe that focusing on Michael's experiences and my own is worthwhile in order to resist dominant narratives about people who die from drug-related overdoses and draw connections to mental health issues.

I also recognize that many observers have been critical of mainstream journalism coverage of the opioid crisis, particularly in the way that some reporters have attempted to humanize white, middle-class people who have experienced fatal overdoses. Critics point to how the empathetic tone of some journalism work is strikingly different than that of dominant media narratives focused on crack cocaine consumption in the 1980s and early 1990s. Many journalism stories that were produced during that period referred to so-called "crack babies" and their largely black, racialized, and vilified mothers (Newkirk II, 2017). *The New York Times* ' editorial board writes:

News organizations shoulder much of the blame for the moral panic that cast mothers with crack addictions as irretrievably depraved and the words enemies of their children. The New York Times, The Washington Post, Time, Newsweek and others further demonized black women "addicts" by wrongly reporting that they were giving birth to a generation of neurologically damaged children who were less than fully human and who would bankrupt the schools and social service agencies once they came of age. (2018, Dec. 28).

Yasmin Jiwani argues that that journalists often fail to document and communicate the experiences of racialized and marginalized individuals. She critically examines media reports about the 1997 beating death of 14-year-old Reena Virk, who was of South Asian origin, by a group of seven girls and one boy who were between 14 and 16 years of age. Jiwani writes: "[A]s with dominant frameworks of meaning that are utilized to cover stories of racialized immigrant and refugee communities—Reena's difference was underscored and inferiorized" (1999, p. 178). She adds that by neglecting to highlight racism as part of what motivated the youths to carry out

the murder, and to disregard it as a factor in the way the judicial system dealt with the crime, journalists' reports were "symbolic of the denial of racism as a systemic phenomenon in Canada" (1999, p. 178).

By focusing this project on Michael and my personal experiences, I acknowledge the stigma that journalism organizations have perpetuated about racialized people who have been impacted by drug epidemics. I am not attempting to claim that Michael's life and the grief that my interlocutors feel is any more painful, significant, or worthwhile of attention that those of others, including members of racialized communities. I believe the nuances of people's experiences related to the opioid crisis that are shaped by institutionalized racism need to be examined and articulated.

#### Collaborating with people who use drugs: Looking beneath the surface

With this doctoral project, I am building upon my earlier research studies aimed at collaboratively producing counter-narratives about the opioid crisis. In 2014, I facilitated a threeday digital storytelling workshop for 10 individuals in the DTES who have used heroin for years (Goodman, 2018a). From 2014 to 2015, I also used documentary photography in order to document the lives of three people in the same neighbourhood who use heroin. At the end of the year, I curated the images and conducted photo-elicitation interviews with the participants. This allowed me to use photographs to invite my collaborators to share their thoughts and feelings about the images and their lives (Prosser & Loxley, 2008, p. 19). I then paired excerpts of audiorecorded conversations with my interlocutors with my photos of them in a web-based and interactive initiative called *The Outcasts Project* (Goodman, 2018b). Doing this provides people who engage with the project additional information in order to understand the backstories of the individuals I photographed (Sontag, 1977, p. 23). In our discussions, the participants shared what Michel Foucault calls "subjugated knowledges," (1980, p. 82) that are often overlooked by scholars and decision makers. Conducting photo-elicitation interviews also helped to establish a sense of equality between the individuals I photographed and myself (Prosser & Loxley, 2008), and enabled them to develop a sense of ownership over the photos.

These two research-creation projects allowed me to spend significant amounts of time with people affected by the opioid crisis and substance use disorder. Through my interactions with my earlier collaborators, I was able to confirm what I already intuited about the connection between suffering and addictive behaviour. Dr. Gabor Maté, a physician who has worked with people who use drugs in the DTES for decades, writes: "Not all addictions are rooted in abuse or trauma, but I do believe they can all be traced to painful experience. A hurt is at the center of all addictive behaviors" (2008, p. 73). The individuals I collaborated with in my previous research projects told me about some of their experiences with abusive or alcoholic parents, sexual and physical abuse, poverty, homelessness, stigma, and struggle to access harm reduction services. Getting to know my research participants and hearing about the challenges they have faced bolstered the sense of urgency I feel about collaborating with individuals like them in order to amplify their backstories for wider publics.

The three individuals who participated in my photo-elicitation project in the DTES were taking part in North America's heroin-assistance treatment program. Its aim was to help people who had not responded to some of the most common treatments for heroin addiction such as methadone. When the program was implemented, a debate was taking place between policy makers and members of the public about whether heroin-assisted treatment should be allowed in this country, even though it has been long been offered across Europe as part of national healthcare programs. The federal Conservative party managed to temporarily shut the program down, forcing its participants to take their case to the Supreme Court of B.C., where a judge ruled they could not be denied treatment that is backed by science. Many people who had read about heroin-assisted treatment were slandering people who use drugs online, referring to them as useless and unworthy. I hoped my research could help humanize some of the individuals who claimed that the heroin-assisted treatment program had saved their lives.

In what follows, I reflect on my experience taking photos of Marie, one of three people who participated in my photo-elicitation project.

It was Friday before Thanksgiving weekend, and I was on a bus with Marie travelling from where she lives in Vancouver's DTES to the neighbouring city of Port Coquitlam. It was the evening rush hour, and the bus was packed with people heading home after work. Marie sat behind the driver, and the fluorescent lights in the bus made her skin look slightly green. Her tabby-coloured cat was in a travel bag on her lap. Marie fell asleep and leaned over the carrying case, cradling the cat like it was the most precious thing in her life. Marie's shoulder-length brown hair was slightly disheveled, and as she slept, she had a slight smile on her face.

I stood holding a hanging strap to balance myself. I glanced toward the back of the bus and saw that many of the commuters were glaring at Marie. Some looked fearful and even disgusted. I crouched on one knee, and took a few photos of Marie, along with a close-up of her cat peering through the mesh of the travel bag.

Marie was on a mission to find her mother whom she had not seen in over two years. She did not have her phone number, but thought she remembered where her mother's apartment building was located. I was travelling with her to document her experience.

Since she was a teenager, Marie had been addicted to heroin. She started using drugs as way to cope with the impact of her mother's alcoholism and the abuse that she endured at the hands of her mother's partner. Marie also sought comfort in drugs, because she felt a lot of sadness due to the fact that the challenges she faced in her youth meant she was unable fulfill her dream of becoming a professional dancer. She had auditioned for the National Ballet of Canada when she was a girl, but her mother, who had been drinking and drove Marie to the audition, got lost on the way. As a result, Marie arrived late, anxious, and was unable to perform as she had hoped.

Marie woke up and I followed her off the bus. I walked with her through the streets and up to a low-rise apartment building. I watched her examine the list of names on the building's intercom system, but she did not see her mother's. She then circled the building on foot, holding her cat, calling out to her mother as loud as she could. Marie returned to the intercom, pressed a button, and her mother finally answered. I watched Marie enter the building and disappear down a hallway. She had allowed me to photograph her in many situations, but she had asked me to not take images of her with her family, so I returned to the bus stop and made my way back downtown. A few days later, Marie told me that the reunion with her mother had been smooth, and that she planned to visit her again soon. I was pleased for her, after all, I understood the pain of separation from one's mother.

A few days later, I was spending time with Marie and taking photos of her at the heroinassisted treatment clinic in Vancouver. I was sitting at a table next to a man who was also taking part in the program. We were speaking informally, and I said that I was not familiar with a particular method of drug consumption that he mentioned. "And you're making a project about drug users?" he asked, implying that I was not qualified to conduct the work I was doing, because I had insufficient knowledge about illicit substances.

I responded that it was not important for me to understand the A to Z about drug use. I briefly explained that I was more interested in understanding and highlighting what lies beneath the surface. As noted previously, I am drawn to explore what leads individuals to use drugs and

helping them tell their stories, as opposed to focusing on the kinds of substances that people consume.

#### Adopting a more participatory approach

My previous research with people who use drugs allowed me to develop insights into the relationship between pain and addiction. My knowledge in this area allows me to view others who are affected by the opioid crisis, including Michael, with a sense of compassion. Although my research is inspired by the intention to create humanizing counter-narratives, this doctoral project is also a departure from my previous work. In my earlier research, I worked in semi-participatory ways. I planned the studies, designed, and facilitated the digital storytelling workshop, and I took the photographs, and conducted photo-elicitation interviews. The participants collaborated with me by creating digital stories about their lives, allowing me to take images of them, and taking part in interviews. I communicated the goals of these projects with these individuals and they expressed their agreement with them. Yet, I had a greater influence than they did in terms of the philosophical orientations of the projects, the methods that we adopted, and the knowledge we produced. In contrast, this doctoral project is designed to be considerably more collaborative at all stages, including its conceptualization, production, and dissemination. Although I came up with the original idea, the methods that we engaged in and the outcomes are a result of a highly participatory process.

In my preliminary discussions with Carina and later with Rose and Andréa while they were still considering whether they wanted to participate in the project, I briefly mentioned my earlier research studies. I wanted to let them know I was familiar with the wider context of the opioid crisis, and I hoped this would allow them to begin to trust me. However, Carina indicated that she thought my previous projects were not entirely relevant. She stated that she did not see a connection between the experiences of people who use heroin in the DTES and Michael's. She said that she was primarily interested in highlighting the links between Michael's mental illness, his death, and the need for greater support for people in similar situations. In response, I mentioned to Carina that I recognized the individuals I had previously collaborated with had different life experiences than Michael, as well as her, Rose and, Andréa. I indicated that I understood both groups of people were positioned to produce different types of knowledge. Yet, I added that my central motivation was to assist people, regardless of their backgrounds, in telling deep and meaningful stories. Part of this process involves articulating how the challenges that individuals have faced in their lives may have contributed to their drug use, and in Michael's case, to his overdose. I also stated that it would be the first time for me to work with bereaved people who were dealing with a loved one's overdose, and that this was something I was interested in doing.

### **Personal experience**

Although I sensed that collaborating with Carina, Rose, and Andréa could be beneficial for them and me as a researcher, I initially felt apprehensive about inviting them to take part in the project. As noted above, I had never met them or Michael before launching the project. Meanwhile, I was asking Carina, Rose, and Andréa to share some of their most painful and private thoughts and feelings with me and wider publics. I knew this was a significant request, particularly because I was essentially a stranger to them. At the same time, I felt that some of the challenging experiences that I have faced in my life made it appropriate for me to lead the study, assist them in producing their testimonies, and create a digital memorial about Michael. I am referring to issues that I have highlighted in the preface, namely that my mother had bipolar disorder, abandoned my family and me when I was young, and that since she died in 2015, I have been coming to terms with many of the events that shaped her life and mine.

Like Carina, I have watched a loved one struggle with mental illness and felt powerless in the face of it. In writing about Michael in a second *Lion's Roar* article, Carina recalled moments when she had observed Michael being impacted by his condition. She writes:

[He] would describe how energized and relentless his mind was, and how much energy he struggled to quell or channel productively. Subtle stressors could trigger a mood shift: a too-itchy sweater, socializing late in the evening, time zone travel, changes in daylight, or unusual diet. A vague incoherent darkness underlay the mania. (2017, para. 8)

In spite of the parallels between our experiences, as indicated previously, throughout the project, I shared only nominal details about my personal life with my interlocutors. However, reading sources by anthropologists such as Mary Louise Pratt (1986), Ruth Behar (1993), Renato Rosaldo (1993), Kirsten McAllister (2011), and Clifford Geertz (1996), whose work I highlight in Chapter 1, allowed me to conclude that it was appropriate for me to draw on my emotions

related to my experiences with my mother in order to connect and empathize with my collaborators. Examining literature on autoethnography, which I also highlight in Chapter 1, led me to also conclude that it was fitting for me to consider my personal life in my responses to my interlocutors' testimonies and share elements of these reflections in this thesis.

#### Shared practices and establishing trust

Beyond having common experience with someone who has struggled with a mental illness, my collaborators and I share something else. All three of the participants have practiced meditation for years. This connected them to Michael while he was alive and has continued to do so since his death. Carina first met Michael while attending meditation sessions and talks that Michael gave at the Centre of Gravity. They later developed a romantic relationship and were married. Rose and Andréa also met Michael at the centre, considered him their primary meditation teacher for years, and attended several meditation retreats that he led in North America and abroad. During this time, they also became close friends with Carina. While teaching meditation in Toronto and on retreats, Michael often asked Rose to assist him. He invited her to lead Buddhist chants and take on other teaching duties. For many years, Rose and Michael had regular discussions, or "interviews," as they are often referred to by Buddhist teachers and practitioners in the West. During these discussions, meditators typically report on challenges that they face in meditation practice and life, as well as things that are going well, and teachers offer guidance and support.

It is impossible for me to fully know or communicate exactly how much of a role meditation has played in my collaborators' lives. Yet, I believe that their commitment to living mindfully and with kindness and compassion was evident in the ways they conducted themselves in all of our exchanges throughout the study. The challenges that they have faced have been immense. For Carina, Michael's passing meant losing her partner and the father of her children. Since his death, she has had to grieve while taking care of her family and planning how they will move forward. For Rose and Andréa, Michael's death meant they lost their meditation teacher and friend, someone who held a very special and unique place in their lives. Throughout the study, I was often struck by how stable the participants seemed to me, even as they experienced difficult circumstances and expressed painful emotions. They attributed their ability to remain balanced and open-hearted to their meditation practice. In Buddhist practice, meditators are encouraged to observe their bodies, feelings, minds, and thought processes (Insight Meditation South Bay, 2014). By doing so, practitioners can develop a sense of peace, happiness, and freedom, according to Buddhist teachers and philosophers (Gunaratana, 2012). I believe that the emotional depth of my collaborators' testimonies is also a reflection of their commitment to meditation and mindfulness practice, because these are known to assist people in being with and processing difficult experiences. I also have a sense that Buddhist practice assisted my collaborators in engaging in deep introspection, which in turn allowed them to create personal narratives that are rarely communicated by dominant media organizations.

For my part, I survived the ramifications of my mother's mental illness and abandonment by learning to sit with my suffering. Since my early twenties, I have practiced meditation and yoga in a fairly consistent and dedicated manner. Taking part in silent meditation retreats that have lasted between 10 days and a month has allowed me to become familiar with the internal and personal repercussions of my mother's mental health and the decisions she made. The first time I sat still for 10 consecutive days on a silent retreat, every single moment I had ever experienced with my mother, and every instance in which I had felt her absence, seemed to play out like a film in my mind. I felt as though all the painful emotions that I had ever experienced in relation to her coursed through my body once more. It was exhausting, but by the end of the retreat, I had begun to appreciate my own resilience. After all, when I was young, my mother was my anchor, my deepest and closest connection, and without her, I felt lost and alone. Over many years, while I continued to practice meditation, I learned to hold myself with a growing sense of compassion, and slowly, I began to feel a sense of greater ease with the difficult emotions that I had lived with for so long.

The fact that my collaborators and I shared a commitment to meditation meant that we were able to establish friendly and positive connections with each other early on. I believe our shared practices allowed my interlocutors to feel comfortable revealing details of their lives in their recordings and conversations with me. My meditation and mindfulness practice allowed me to listen and bear witness to all that ==they shared with me in an accepting way. On meditation retreats, teachers often lead practitioners in what is known as "taking the precepts," or vowing to conduct themselves in ethical and non-harmful ways. The five precepts, common to all Buddhist schools, urge practitioners to refrain from killing stealing and lying, and to abstain from harmful sensual conduct, and taking intoxicants (Buddhagosa, n.d.). In my experience, being on meditation retreats where all those who are present have taken the precepts has allowed me to feel safe and at ease. I recognized a similar feeling of comfort and trust while working with my

collaborators on this project. As a researcher, I was also bound to conduct the study ethically and respect the Tri-Council Policy on Ethical Conduct for Research Involving Humans (TCPS or the Policy).<sup>10</sup> I discuss how I did so in Chapter 6 and how a respect for ethics was critical for working with the participants.

Throughout the project, I communicated with my collaborators by Skype, email, and occasionally by telephone. While we worked together, I lived on the Sunshine Coast in B.C. Carina lives relatively close by in the Gulf Islands, but travel between our respective locations requires driving long distances, taking multiple ferries, and can take nearly a full day. Meanwhile, Rose lives in Toronto, and Andréa was based in a small city in Mexico throughout our collaboration. It therefore worked well for Carina and Andréa to primarily audio-record their testimonies using their iPhones. After they sent me their recordings and I listened to them, we had follow-up discussions, mostly over email.

Rose preferred to record her testimonies while speaking directly with me on Skype, often answering questions that I asked her. Early on in the project during these semi-regular exchanges, I recognized that the atmosphere of these conversations felt similar to when I have had interviews on retreat with meditation teachers. I suspected that my discussions with Rose may have felt somewhat similar to those she had with Michael while he was alive. Yet, there were important differences between the discussions that Rose and I had and her interviews with Michael. First, Rose and Michael had a very close student-teacher relationship. It was not possible or appropriate to try to replicate that sense of closeness in our work together. Second, neither Rose or I presented ourselves as meditation teachers, experts, or even more as experienced than the other in meditation. I consider that each time I meditate I am starting with a "beginner's mind" (Suzuki, 2010). I appreciated how we engaged in dialogue as equals, and I made sure to let Rose know that I was not trying to replace Michael in her life, even though as a researcher, I often asked her questions in a way that I imagine he likely did.

#### **Thesis structure**

The written component of my thesis is divided into six chapters. Chapter 1 contains a review of scholarly sources in several areas that informed this project, including

<sup>&</sup>lt;sup>10</sup>The TCPS or the Policy is joint policy of Canada's three federal research agencies – the Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council of Canada (NSERC), and the Social Sciences and Humanities Research Council of Canada (SSHRC). http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/Default/

autoethnography, research creation, shared authority focused on oral history and crossdisciplinary research, participatory documentary, digital memorialization and countermemorialization, witnessing, reflexive anthropology, standpoint theory, the narrative approach, and continuing bonds theory. Researching these fields allowed me to conceptualize and later adapt the project. Examining research-creation enabled me to see that it was possible for me to construct a media project and write a critically-informed thesis about the process, as opposed to producing a purely theoretical thesis. After years working as a journalist, photographer, and documentary maker, I was interested in continuing to create media as part of my doctoral project in ways that were informed by critical thinking and theory. As noted previously, exploring sources on autoethnography allowed me to see that it was appropriate for me to draw and reflect on my life experiences in order to connect with my interlocutors, witness, and amplify their experiences. Literature on shared authority and participatory documentary affirmed to me the value of working in collaborative ways with the participants. Scholarly sources about digital memorialization and counter-memorialization helped me design the project in particular ways in order to resist dominant media narratives and humanize Michael. I was familiar with notions of witnessing from meditation practice, which involves observing one's inner experiences and external conditions. Yet, I was interested in exploring how humanities scholars have written about witnessing, and how I could incorporate this in the project. As mentioned previously, literature on reflexive anthropology was instructive for me, because it also showed me that it was fitting and even helpful to include my own emotions in the study. By collaborating with three women, it was critical that I turn to standpoint theory in order to ground the study. Exploring sources on the narrative approach and continuing bonds theory allowed me to shape the types of questions that I asked my interlocutors, and I believe this influenced their testimony recordings in vital ways.

In Chapter 2, I examine scholarly sources focused on the case study approach, and explain how these helped me to recognize the value of working with my interlocutors in order to tell stories about Michael, as opposed to collaborating with a wider group of people who are connected to other individuals. I discuss my rationale for creating a counter-memorial about Michael and framing the project in this way. I examine my intention to humanize Michael in order to resist dominant narratives, and to highlight the connection between mental illness and overdose deaths. I explore my goal of trying to generate empathy among publics and decision makers who engage with the project, and I problematize this notion as well. I explore a small

number of counter-memorials focused on the opioid overdose crisis and a number of countermemorials that were constructed in response to historical events, tragedies, and critical social issues. These include the Air India disaster, violence against women, the massacre at Montreal's Ecole Polytechnique, the Holocaust, and human rights violations in the Occupied Palestinian Territories. Examining these projects allowed me to recognize that producing a countermemorial with my collaborators enabled us to resist dominant narratives about the opioid crisis and individuals who experience fatal overdoses.

Chapter 3 features a discussion of oral historian Henry Greenspan's method of collaboratively producing testimonies with Holocaust survivors over more than 40 years, which he describes as "learning together" (2010a, p. xii) and "knowing with" (2010a, p. 230). Exploring Greenspan's approaches helped me devise a method of engaging with my collaborators in order to record their testimonies and produce the digital memorial in a collaborative way. I discuss how Greenspan and others who have built upon his approaches have allowed them to co-produce unique knowledge, and how their methods contrast with strategies that have been institutionalized by influential historical organizations. I highlight how these scholars' work has been beneficial for witnesses and researchers.<sup>11</sup> I also explore some of the ethical and methodological challenges that Holocaust testimony researchers have encountered. I discuss why Holocaust testimony research has personal resonances for me, namely because of my grandmother's wartime experiences and my connection to her. I re-examine the notion of trauma and the risks of emotionally or psychologically upsetting witness. I end the chapter by highlighting the potential for commodification, voyeurism, and cultural colonialism of grief, as well as cultural expectations that have influenced the nature of Holocaust testimony.

In Chapter 4, I explore how the participants technically recorded their testimonies and the frequency of our communication. I refer to participatory interactive projects, including *The Quipu Project* (Lerner & Court, 2015), *Blood Sugar* (Daniel, 2010), and *86 ½ Years* (Usborne, 2017), that prioritize audio testimonies, and explain how they were inspiring and suitable models for the digital memorial that we constructed. The chapter contains an analysis of how two test listeners, Erin Robinsong and Katherine Kline, and I view the participants' recordings as counter-narratives. I explore how I invited my collaborators to experiment with Lorraine Hedtke and John Winslade's (2016) theory of crafting grief. It is an agentic and creative way that

<sup>&</sup>lt;sup>11</sup> When discussing Greenspan's research in this thesis, just as he does, I use the words survivor, witness, collaborator, and participant interchangeably to refer to Jewish Holocaust survivors whom he conducts his research with.

bereaved people have adopted in order to remember people who have died and communicate their grief. I also examine how we applied the continuing bonds theory from narrative psychology. I discuss how by building upon this method, I invited my collaborators to reflect on their ongoing connections to Michael and speak with him in the present. The chapter then features a deeper analysis of the testimonies that was produced by engaging in one-on-one conversations with my interlocutors roughly a month after the digital memorial was first published online. I also share highlights of my autoethnographic responses to my interlocutors' recordings.

Chapter 5 contains a brief explanation of interactivity. I discuss why I chose the interactive software, Klynt, in order to create the project online. I also explore some of the affordances and limitations of creating interactive initiatives. The chapter contains an analysis of two participatory interactive projects, *The Quipu Project* (Lerner & Court, 2015) and *Blood Sugar* (Daniel, 2010), that feature audio testimony in central ways. I then focus on how my interlocutors and I planned the online project. I discuss how they curated their recordings, how I view their material as "difficult knowledge," and the implications of this for the project. The chapter then features a discussion of how we shared authority, and how I briefly considered making the digital memorial an open space project (Zimmerman & De Michel, 2017), which is a type of online initiative that enables an expanding number of people to contribute and shape it. I explore how I ultimately chose not to adopt this approach after consulting with my collaborators. In doing so, I recommitted myself to making all decisions together and supporting them to produce a digital memorial that aligned with our original vision of using only their contributions. The chapter ends with some highlights of other challenges that I encountered in the project.

In Chapter 6, I discuss how the impermanent nature of the digital memorial feels appropriate, and I refer to other memorials that were deliberately constructed in order to not last forever. I also explore the ethical and political issues that I considered while producing the project. I then turn to how I plan to reach publics and policy makers with the digital memorial and share the knowledge that I have acquired with others. The thesis ends with an examination of areas for future research.

# **CHAPTER 1**

# THEORETICAL ORIENTATION AND LITERATURE REVIEW

# Introduction

The purpose of this literature review is to highlight particular themes within a range of scholarly fields that informed and guided the methodologies that I adopted in this study. I have primarily focused on topics that help to articulate the specific ways that I collaborated with the project's participants to produce their testimonies and a digital memorial in order to challenge dominant narratives about the opioid crisis and people who experience fatal overdoses. I begin with the topic of research-creation in order to situate this project. Thereafter, I examine scholarly sources focused on participatory documentary, digital memorialization, counter-memorialization, reflexive anthropology, standpoint theory, as well as the narrative approach, and continuing bonds theory. Given that Henry Greenspan's method of collaborative testimony production significantly influenced the philosophical orientation and methods that I adopted with my collaborators, I devote Chapter 3 to a discussion of these themes.

# Autoethnography

From the time I was in early twenties, I immersed myself in my work as a journalist, documentary maker, and researcher. My mother had been missing for roughly 15 years, and as just as I began to launch my career, she was found. We started to rekindle our relationship, but it took years for me to begin to heal from the challenges brought on by her mental illness and disappearance. I did not fully recognize it at the time, but her sickness and abandonment led me to focus my work in a particular direction. I found myself frequently reporting on people who were searching for their own loved ones—individuals who had gone missing in armed conflicts and natural disasters in places like East Timor, Nepal, Cambodia, and Sri Lanka. Although my mother had not been lost in a war or disaster, like many of the people I met in the field who were desperate to find family members, I knew what it was like to have a loved one go missing. For years, I had grappled with the pain of not knowing if my mother was dead or alive, and if I would see her again.

I never spoke of my personal life with the people whose stories I explored. I did not want to equate my suffering with theirs, and I was always mindful of my privilege as an educated,

white male from an economically-developed country. I made a conscious decision to keep my past separate from my work, at least in my discussions with those I met in the field and in my published work. However, each encounter with someone who had experienced significant personal loss, each act of witnessing and each interview, brought me closer to the circumstances of my own life. Reporting on others who faced harrowing challenges, forced me to acknowledge the depth of my own emotional pain. I often considered whether by immersing myself for lengthy periods in remote places that had been marked by conflict and disaster, if I was trying to deny or outrun my suffering, but in reality, I was doing all I could to heal from my past.

When it came to conceptualizing and producing this doctoral project, my mother's mental illness and abandonment also motivated me to want to work with people who knew and loved Michael. As noted previously, I felt it was appropriate for me to bear witness to their suffering and help them in sharing their memories of Michael and speaking about their grief. Yet, in my discussions with my interlocutors, I rarely spoke about my personal life. My intention was to be present for them as much as possible, to listen attentively, and to act with compassion and kindness.

It was only after we curated and edited the women's recordings and published the digital memorial that I began to examine sources on autoethnography. Doing so prompted me to make connections between my interlocutors' narratives and my personal experiences related to my mother's mental illness, disappearance, and death. In what follows, I highlight how exploring sources on autoethnography compelled me to adopt a new strategy in the project, which I found rewarding, and is hopefully beneficial in terms of the knowledge that I am able to share in this thesis.

Carolyn Ellis defines autoethnography as "research, writing, story and method that connect the autobiographical and personal to the cultural, social, and political" (2004, Preface, para. 51). She adds: "We'll view ourselves as a part of the research—sometimes as our focus—rather than standing outside what we do. Instead of starting with the hypothesis, we'll emphasize writing as a process of discovery" (2004, Class One, para. 16).

Ellis encourages researchers to begin written projects by presenting narratives that highlight their personal experiences and perspectives, how they relate to the issues and people they are working with, and how their individual insights can assist them in their explorations (2004, Class Two, para. 2008). In a discussion with her students, who were being introduced to autoethnography, one student named Leigh pointed out that rather than simply positioning herself in her research, by recounting some of her personal experiences, she was attempting to "intertwine" herself with her research participants' lives (qtd. in Ellis, 2004, Class Two, para. 208). Leigh explained that as she reflected on her engagements with her collaborators, she also tracked and documented how she was changing as a person in the process. Barbara Tedlock refers to this type of research as "narrative ethnography" (1991, p. 78). According to Ellis, it takes place when "the ethnographer's experiences are incorporated into the ethnographic description and analysis of others and the emphasis is on the *ethnographic dialogue or encounter* between the narrator and members of the group being studied" (2004, Class Two, para. 212).

Taking cues from Ellis, in the preface and introduction of this thesis, I outline how my personal experiences, in part, led me to conduct this project, and I recall different moments in my life. In Chapter 4, I share further details about how the process of listening to my interlocutors' testimonies personally impacted me and led me to reflect on my experiences (Ellis, 2004, Class Two, para. 217).

Prior to experimenting with this approach in this thesis, I questioned whether disclosing parts of my personal life could be helpful for the participants and readers. However, by sharing details of my own experiences, I aim to provide readers with a clearer sense of my perspective and positioning as a scholar exploring this field. Ellis insists: "Readers want to know why they should believe you" (2014, Class Two, para. 219).

My experiences surrounding my mother's mental illness and disappearance were so formative to me in my youth that I have frequently felt a desire to examine them in my creative work, although as I have noted, not in my journalism, documentary work, and research. In 2007, I produced a radio documentary titled, *Let the Water do the Work*, for a program called *Outfront* on CBC Radio. In the 12-minute piece, I recorded conversations with my mother in which I invited her to share her feelings about her bipolar disorder and our family's breakdown. Following her death, I spent a year and a half collaborating with the NFB in order to explore whether there was potential for us to make an interactive documentary together focused on my experiences with my mother. In the end, we opted not to complete the project, mostly because the subject matter felt too vast. We struggled to narrow the story to a few key moments. I am currently writing a series of short stories about my experiences with my mother, but aside from the radio documentary that I produced, I have not shared details about these issues with people other than close friends and family members.

Ellis indicates that some scholars are critical of autoethnographic research and claim it is not a "legitimate social science" and is void of any "systematic analysis." She adds that it is "described as atheoretical . . . [and] places too much emphasis on the literary, aesthetic, emotional, and therapeutic" (2016, Chapter 10, para. 16). However, like Ellis, I concluded "that it didn't matter whether my work was viewed as social science or even sociology, and that I was interested in the creative, artistic possibilities of what I was doing as I was in the scientific ones" (2004, Class Two, para. 117).

By adopting an autoethnographic approach, my intention was to reflect on my own experiences and interactions with the project's participants in order to bolster my understanding of their lives, their connections to Michael, and their grieving processes. I attempted to replicate the approach that Ellis has adopted in her own studies. She explains:

I start with my personal life and pay attention to my physical feelings, thoughts, and emotions. I use what I call 'systematic sociological introspection' and 'emotional recall' to try to understand an experience I've lived through. Then I write a story. (2014, Preface, para. 29)

In doing so, Ellis explains that she tries to gain a greater understanding not only of herself, but of others. Although I initially thought that reflecting on my life and writing about it in this thesis would prevent me from being fully available for my interlocutors, Ellis insists that concerns of this nature are not credible. She argues:

[T]elling our stories is a way for us to be present for each other; the act provides space for us to create a relationship embodied in the performance of writing and reading that is reflective, critical, loving, and chosen in solidarity. (2004, Introduction, para. 18)

Although I was interested in recalling parts of my past, I had some reservations about doing so in an academic context. Given the widespread stigma that still exists about mental illness, I felt apprehensive about including too many details about my mother's experience. In an early draft, I simply summarized the issue, noting that she had suffered from bipolar disorder in my youth, and that it impacted virtually every facet of our lives. I hesitated to elaborate and highlight the fact that not only had she been unwell, but she abandoned my family and was missing for a large part of my youth. I pictured members of my doctoral committee reading the thesis and potentially judging me or coming to conclusions about the kind of person I am. I felt concerned that this could somehow affect how my work was perceived. Ellis notes that many researchers have had similar concerns and have chosen to write "confessional tales," but kept them "separate from the research document than a chapter in a dissertation or book" (2004, Class Two, para. 154). She adds that some scholars have believed that revealing elements of their personal lives could "undermine" their research or result in their work not being published (2004, Class Two, para. 154). Others, Ellis explains, have used pseudonyms as a form of protection, because they have felt that outing themselves could potentially damage their careers or reputations (2004, Class Two, para. 154). I have nothing to be ashamed of. I have never suffered from mental illness, and even if I had, that would not be a reason to hold back from sharing my details of my life in my doctoral work. Yet, as Ellis suggests, scholars who do share elements of their personal experiences will inevitably have their lives "scrutinized and critiqued" (2004, Class One, para. 156). Tony Adams, Stacy Holman Jones, and Ellis add that autoethnographic research "always carries personal, relational, and ethical risks" (2015, Introduction, para. 19).

In the end, I accepted the possibility of being judged, but I trusted that members of my doctoral committee would see value in the approaches that I experimented with. If fellow researchers and other readers look down on me, I will likely never know, and it does not really matter to me. Ellis explains that while her husband, Gene, was dying, she kept detailed notes about her experience as a way to deal with it. She explains: "Thinking sociologically provided a coping mechanism. I wanted to write my story to help others understand their experiences sociologically" (2004, Class One, para. 162). For Ellis, writing about herself in the midst of a challenging time was not only intended to help alleviate her suffering. She hoped that by sharing her personal insights she could assist others who face similar situations. Adams, Holman Jones, and Ellis insist that they hope they can "encourage you to embrace writing and telling stories as not only a way of life but also a way to make life better—for you and for others" (2015, Introduction, para. 19). Examining my inner life in the context of this project allowed me to see that almost three and a half years after my mother's death, a lot of the emotional pain that I experienced as result of her mental illness and abandonment in my youth still feels raw to me. Like Ellis, I hope that disclosing elements of my life in this thesis may be of some assistance to

others who may read it and who may also have experience with a loved one who has suffered from a mental illness.

As noted previously, throughout the project and in my final discussions with my interlocutors in which I invited them to closely analyze their recordings, I chose to keep most of my personal experiences to myself. I was mindful that speaking about myself could, as Ellis claims, "interfere with or change the story that is told" (2004, Class Three, para. 49). Ellis asks: "How do we include ourselves as researchers yet not take over the story of the other?" I reflected on this question and opted to simply inform my interlocutors that I would add more information about my personal life in the written thesis.

# **Creation as research**

As noted in the introduction, while conceptualizing the project, I recognized that I had the option of utilizing traditional research methods, such as conducting media analyses and semistructured interviews with my collaborators. However, I was interested in adopting innovative methods and making media production a central element of the study. It is important to note though, I do not view the project solely as belonging to the realm of production. It is critical for me to situate myself as a scholar-practitioner in the field of communication studies and to outline what makes the project research-creation.

Scholars at Concordia University, including Owen Chapman and Kim Sawchuk, have played a critical role in theorizing research-creation. Their work has led to a growing number of PhD and masters students adopting research-creation as integral elements of their work. These were key factors in my decision to pursue my doctoral studies at Concordia. As noted previously, I was interested in building upon my previous research-creation projects and my experience as a journalist, documentary maker, and photographer. I am grateful to be part of a growing community of scholars who are committed to research-creation, and I am looking forward to conducting further research projects of this nature.

Chapman and Sawchuk's work (2012) aimed at defining research-creation led the Social Sciences and Humanities Research Council (SSRHC) to accept research-creation as a legitimate qualitative research methodology in the social sciences and humanities in 2013. SSRCH defines research-creation as "an approach to research that combines creative and academic research practices, and supports the development of knowledge and innovation through artistic

expression, scholarly investigation, and experimentation" (n.d.). It adds that research-creation involves the production of "critically informed work in a variety of media (art forms)" (n.d.).

SSHRC's recognition of research-creation has opened up pathways for artist-scholars to use a wide range of practices in order to produce knowledge and contribute to discussions about a number of important issues. A number of doctoral students in communication studies at Concordia have created interesting research-creation projects. For example, Azra Rashid's 2016 project involved documentary video production and testimony interviews with female survivors of the genocide in Bangladesh that took place in 1971. In the UK, research-creation is known as "practice-based research" or "practice-as-research." Ceyiz Makal Fairclough (2013), a doctoral student in Media Arts at the University of Salford, used photography and photo-elicitation to resist dominant visual representations of migrants. Cahal McLaughlin (2007) produced an audiovisual documentary consisting of testimonies and memories of prisoners in Northern Ireland and South Africa who were involved in political violence as part of his doctoral project at the Royal Holloway University of London. Exploring these research-creation projects helped me to see that participatory audio-visual production can allow researchers and participants to create knowledge in ways that would not be possible in traditional scholarship.

Chapman and Sawchuk (2012) outline four different forms of research-creation. They are research-for-creation, research-from-creation, creative presentations of research, and creation-asresearch. They add that it is possible for scholars to adopt more than one approach to researchcreation at the same time. In this project, I engaged in two types of research-creation: researchfor-creation, and creation-as-research. When it comes to the first category, my work involved "an initial gathering together of material, ideas, concepts, collaborators, technologies, etcetera, in order to begin" (Chapman and Sawchuk, 2012, p. 15). I read about the opioid crisis in order to understand the gravity and complexity of the situation. I also read about Michael and listened to many of his podcasts. Hearing his voice enabled me to develop an appreciation of who he was and the depth of his knowledge about meditation and yoga. I read sources by Greenspan and other testimony scholars, and listened to audio and video-recorded testimonies with Holocaust survivors. I explored research by scholars who specialize in autoethnography and reflexive anthropology, which allowed me to conclude how I would position myself within the project and utilize my personal experiences in order to connect and empathize with my collaborators. As I discuss in Chapter 5, exploring literature on participatory documentary and the CFC/SN, led me to shift my original position of having full editorial control over the final project to inviting my

collaborators to censor their content. I also examined scholarly work focused on standpoint theory, digital memorialization, counter-memorials, and witnessing. Exploring sources on the narrative approach and continuing bonds theory prompted me to invite the participants to speak with Michael in their testimonies and during our conversations. These approaches allowed me to assist the participants in "revealing" (Chapman and Sawchuk, 2012, p. 15) their personal narratives in their recordings and the digital memorial.

I also viewed my work with the participants as what Chapman and Sawchuk (2012) describe as "creation-as-research" (2012). They define this type of scholarship as

the elaboration of projects where creation is required in order for research to emerge. It is about investigating the relationship between technology, gathering and revealing through creation . . . while also seeking to extract knowledge from the process. Research is more or less the end goal in this instance, although the "results" produced also include the creative production that is entailed, as both a tracing-out and culminating expression of the research process. (2012, p. 19)

Engaging in sustained and frequent dialogue with my collaborators prepared them to record nuanced testimonies about their connections to Michael and their experiences with grief. Designing the digital memorial provided us with a platform for housing and sharing these narratives with others. This collaborative process also informed the participants' choices about how they curated and edited their recordings. Together, we determined that excerpts of their testimonies ranging from five to seven minutes would allow listeners to hopefully stay engaged with the project and come away with a blended experience.

Lisa Henderson claims that research-creation involves a combination of "knowledge production and expressive invention" (2017). She adds it allows researchers to develop innovative modes of inquiry that scholarship within disciplines often lacks. Henderson notes that research-creation is increasingly used by communication studies scholars and that it can be helpful while addressing issues related to "representation, cosmopolitan justice, voice, moral calculus" (2017).

Natalie Loveless argues that "practice and research are messy and entangled" (2012, p. 103). She claims that it allows scholars to produce original narratives, but it requires them to

develop new skills and experiment with innovative modes of disseminating knowledge (2015, p. 53). Given the urgency of economic inequality and environmental degradation, Loveless insists that research-creation opens up unique pathways of addressing issues such as these (2015, p. 54). Given that thousands of people have died from opioid-related overdoses in North America, I think it is appropriate to explore the potential for research-creation to help researchers and affected individuals highlight the impacts of this crisis and encourage authorities to respond to it more effectively.

Sarah Niblock argues that the process of producing journalism can be considered a form of research in action. Just like journalism, my work with my interlocutors was informed by research that I conducted prior to collaborating with these individuals. It was also influenced by our attempts to find answers through our work together. We were motivated to counter dominant modes of representing the opioid crisis and people who experience fatal overdoses overdose. Does the digital memorial represent a "solution to a question" (2012, p. 56), as Niblock suggests journalism can? I do not believe the digital memorial, the articulation of our collaborative processes, and the analysis of the outcomes that I share in this thesis, point toward clear answers. Rather, they reflect a particular way of working together, and the nature of people's experiences, which I think are valuable.

#### **Shared authority**

In light of the collaborative nature of this project, I found it helpful to examine how oral history scholars and media producers have worked in participatory ways and attempted to "share authority" with a range of participants and communities. One of the seminal projects that I explore is the Montreal Life Stories (MLS) project, led by Steven High. In this section, I also examine the approach that participatory documentary filmmaker Elizabeth Miller has adopted. I also devote considerable attention to participatory filmmaking practices developed by the NFB in the 1960s that continue to inspire many filmmakers.

# Oral history and cross-disciplinary collaboration

The MLS project, funded by SSRCH, enabled a large group of faculty members, community-based researchers, and a number of community partners to work together from 2015 to 2012. Their central mission was to support members of the city's Rwandan, Haitian, Cambodian, and Jewish communities who had survived genocide and violence to tell their personal stories. Throughout the project, more than 300 faculty members connected to Concordia, as well as artists, members of the community, and students were involved in the initiative. At its core, the project was intended to allow participants to produce testimonies together in a manner that historian Michael Frisch first referred to in 1990 as "shared authority" and elaborated on in 2003. Frisch describes this approach as an inclusive and democratic means of documenting and creating "a source of historical information and insights" and a way to obtain the perspectives of individuals and communities that have often been "neglected" by researchers (2003, p. 9). He insists that collaborating with people who are not university-based researchers is important in order to challenge power dynamics that have dominated historical inquiry. Frisch adds that it is "a way to communicate with the past more directly, to be presented with a somehow purer image of direct experience" (2003, p. 9).

High insists that the "dialogic nature" of collaborative interviews allows researchers and respondents to produce unique forms of knowledge (2014, Introduction, para. 7). He builds upon Frisch, who explains that personal interviews allow oral historians to shed light on wider issues by supporting people in communicating their "idiosyncratic reminiscences" (2003, p. 59). High refers to Greenspan, who claims that a "good interview is a process in which two people work hard to understand the experience of one person: the interviewee" (2010a, p. xvi). High argues that participatory research projects function in a similar fashion (2014, Introduction, para. 7). He explains that the purpose of sharing authority is to incorporate participants' areas of specialization, and to treat community partners "not just as subjects of research, but partners in research" (2007). In traditional research interviews, scholars determine the nature of the information that they hope to solicit from interviewees, come up with the questions, and ask them. In this research paradigm, interviewees have little agency. In the MLS project, High and his colleagues approached dialogue with community members differently. In interviews, priority was given to the values of "respect, deep listening, and dialogue" (2014, Chapter 1, para. 31). Rather than dictating the subject matter of interviews, those asking questions were encouraged to "follow the lead of the interviewee whenever possible" (2014, Chapter 1, para. 31). Carole Vacher (2009) took part in the project as an interviewer and indicated that the collaborative approach to questioning people about their life stories allowed her to "share authority" and build "an undeniable relationship" with her respondent (qtd. in High, 2014, Chapter 1, para. 56). Not all interviewers involved in the MLS project reported that they succeeded in fomenting the same level of collaboration. However, citing Frisch, High claims that "sharing authority is a beginning

and not an end." He adds: "It is something that we strive for as oral historians" (2014, Chapter 1, para. 78).

For High, working collaboratively and "sharing authority" means more than conducting interviews in an egalitarian way. He argues that it involves working with research participants in order to build "trust" and make decisions together (2014, Introduction, para. 27). It requires that scholars make "a deliberate decision to give up some control over the product of historical inquiry," according to Katherine Corbett and Howard Miller (2006, p. 20). Miller, Little, and High argue that "sharing authority" means being willing "to open up to new ideas, tools, media, methods, and relationships" (2017, Introduction, para. 7). Working in this way was important to me, and I aimed to develop a rapport with my interlocutors that would allow them to feel comfortable sharing personal details with me. I also consulted the participants on all aspects of the project, including the ways in which they recorded their testimonies, the issues that they would examine, how the digital memorial was structured and would be used, and more.

I discovered that working in a genuinely participatory manner meant it took longer to complete the project than I anticipated at the outset. I found that my interlocutors were often preoccupied with other responsibilities and out of touch for lengthy periods. At times, they also wanted to communicate with me in depth about details of the project, primarily about the photographs that we used in the digital memorial. Linda Shopes describes collaborative research as "long-haul" work, and because of the challenges that this creates, both for researchers and collaborators, she claims there have been relatively few genuine examples of this type of project (2002, p. 585-98). Linda Tuhiwai Smith is a Māori researcher who echoes Shopes, and states that working in collaborative ways requires working together for lengthy periods of time and being mindful of respecting participants' agency in order to avoid imposing a particular vision or method on them (2013, p. 5, p. 16). Miller, Little, and High insist that working at a slower pace is essential in order for scholars to reflect on their philosophical orientations and approaches in a meaningful way. They admit that working in participatory ways can complicate research in some instances. However, they claim that this approach is necessary in order to disrupt power relations that have characterized academic research with community members, "to learn from each other and from our respective projects new ways to theorize, co-create, and take work public" (2017, Introduction, para. 10).

High recalls how when he shared details about the MLS project with other scholars, he faced some skepticism and even some criticism. He recalls a historian barraging him with

accusations that the oral history project could be manipulated or co-opted by its interlocutors. This particular academic was essentially claiming that university-based scholars are the only individuals who are qualified to conduct research. According to High, some scholars questioned whether individuals who told their stories as part of the project could provide valuable or worthwhile information (2014, para. 8). Others have criticized participatory projects, claiming that storytelling projects in which community members share emotion, may not necessarily compel citizens or decision makers to try to create change. Critics caution that there can be reasons to be weary of potentially exploiting participants' and creating a sense of false hope, because by sharing their testimonies, they may want to bring about social and political change (Miller, Little, and High, 2017, Introduction, para. 39). Historian Joy Parr (2010) encourages scholars to work closely with community members and to witness and assist them in documenting their experiences, as opposed to becoming overly entangled in examining theory and method. In contrast, sociologist Beverley Skeggs (2004) claims that academics, given their relative privilege, need to think seriously about their motivations to rely on members of vulnerable populations in order to develop insights about themselves. Alicia Rouverol argues that scholars should not be discouraged from working collaboratively with marginalized communities, but when they do, they must take "power dynamics" into account and invite participants to take up active roles in "the editing and/or publishing process" (2003, p. 63).

Conducting research with community members involves other risks. Katerina Cizek insists it is vital for scholars, media producers, and other participants to clearly articulate their expectations for projects that they are working on together. She warns about the hazards for those who are initiating projects of promising "things that you can't deliver" (qtd. in Miller, Little, and High, 2017, Introduction, para. 72). She adds that she has learned that if participants have expectations about outcomes that are not met in their minds, it can lead to "a lot of hurt feelings" (qtd. in Miller, Little, and High, 2017, Introduction, para. 72), something that I also experienced upon completion of this project.

As noted previously, after we published the digital memorial, I had a round of final discussions with my collaborators, in which I invited them to analyze their recordings in a deeper manner than they had previously. I also expressed interest in hearing their thoughts and feelings about the project. In my discussion with Carina, she stated that she was disappointed with the look of the final online project, and not its content. She indicated that in her view it does not appear as technologically sophisticated as some of the interactive projects that I shared with her

and the other participants at the outset of our work together. I listened and stated that many Klynt projects, including ours, can seem somewhat basic in contrast to interactive initiatives produced by large media organizations such as the NFB. I added that some people who create interactive projects hire designers and coders, but given the participatory nature of this initiative, I made a conscious decision not to do so. It stated that was important for me that we did all of the work ourselves. In making that choice, I was mindful of Marsha Kinder, who writes that when creating interactive initiatives with marginalized populations, it is crucial to not contract "content provider[s]" or "technical experts" and charge them with the task of creating cutting-edge projects. She writes that to do so "inevitably results in a form of colonization" (2003, p. 109).

In hindsight, I accept my responsibility for not articulating my philosophical orientation, priorities, skills, and limitations (i.e., that I am not a savvy interactive designer) with my interlocutors in greater depth. I see that I may have created a sense of false hope, and I regret that. From the start of our work together, I tried to emphasize process more than the final product. Had I expressed this more clearly with my interlocutors at the outset and throughout the project, I could have potentially mitigated the risk of them being disappointed with the final outcome. I also understand that given the personal nature of the memorial that Carina, Rose, and Andréa would want to present it in the most sophisticated way possible.

Throughout the year in which we worked together on the project, I consulted with Carina and my two other interlocutors on many occasions about the conceptualization, design, and presentation of the digital memorial. Each time they provided feedback about the project, which mostly had to do with which images they wanted to use and where they wanted me to place them. I gladly incorporated all of their suggestions. Prior to my final discussion with Carina, none of the participants expressed any concern to me about the way the project looked or functioned.

Where does this sense of disappointment mean for the project and its dissemination? I will consult with Carina and my two other interlocutors to ask how they would like to proceed. Carina raised the question of whether they would be permitted to hire an interactive designer to make any changes that they see fit. I indicated that I would have no objections to that, and I reiterated that they own the content of the digital memorial. If the participants choose to go in that direction, I will understand and accept their choice. However, if that is the outcome, I will feel dissatisfied, because it will mean the project that we created will not reach more people in its current form. And I feel proud of the work we did together and of the final results.

There are other risks of sharing authority that I would like to briefly examine. Technological advances have enabled a growing number of researchers, documentary makers, artists, and individuals who work at museums to produce creative projects with community members. However, individuals who lead projects must be mindful of not exploiting participants and of respecting and protecting their privacy, particularly in light of the growing concerns about data mining (Miller, Little, and High, 2017, Part 1, 1. Rethinking Engagement, para. 6).

In spite of these concerns, ethical research that is conducted by scholars in collaboration with community partners, is increasingly respected and practiced by academics in a wide range of fields. It is now recognized by SSHRC as a legitimate and important form of research (High, 2014, Conclusion, para. 9). High explains that "sharing authority" is not a new concept, and that it is connected to the work of Paulo Freire (2000), the educator from Brazil, who emphasized the value of educators and researchers collaborating with vulnerable populations in order to support equity and fairness in society (High, 2014, Conclusion, para. 9). Inspired by Freire, High notes that researchers are developing innovative ways of working with citizens, and allowing their approaches to be informed by asking questions such as, "Who is this research for?" and "Who does it benefit?" (High, 2014: Conclusion, para. 10). According to Byron White, some of the hallmarks of projects in which authority is genuinely shared are "reciprocity, mutual benefit" and relationship-building that is required in order to forge "democratic partnerships" (2010, p. 67). He adds that feminist scholars, including oral historians, have worked in collaborative ways for decades and have contributed to the development of this field.<sup>12</sup>

High explains that engaging community members as research collaborators can allow scholars to avoid practicing what he calls "academic voyeurisms, or the foreign disciplinary gaze, while still retaining a critical edge" (2014, Conclusion, para. 18). Yet, how can this type of work be helpful for non-academic collaborators? Referencing sentiments expressed by individuals he has worked with, High explains that it can create ways for people to develop greater insights about their personal experiences (2014, Conclusion, para. 24).

# **Participatory documentary**

In this section, I examine some of the approaches that participatory documentary makers in Canada have taken while working with marginalized communities. I begin with brief

<sup>&</sup>lt;sup>12</sup> Many feminist scholars have worked in participatory ways. For example, two of these academics are Denise Baillargeon (1993) and Joan Sangster (1994).

reflections about Elizabeth Miller's work, and then turn to an in-depth exploration of the philosophical orientation that the NFB adopted in the 1960s with CFC/SN program. Reflecting on these participatory documentary methods allowed me to ground my project in a long-standing and evolving tradition.

# **Elizabeth Miller**

One of the reasons I chose to complete my doctoral studies at Concordia University was because of my interest in learning more about Miller's extensive work as a participatory documentary maker and researcher. As part of the MLS project, Miller conducted photography and storytelling workshops with youth from refugee communities. One of her other participatory projects that I have found relevant to my project is Miller's film, *The Water Front* (2007). In producing the documentary, Miller worked closely with a number of residents and community organizations who have been impacted by water privatization in the Michigan town of Highland Park. According to Miller, the issue was not only important to local decision makers or environmentalists, but states it is "quickly becoming the issue of our times" for this particular community and others (2009, p. 59). In order to communicate a nuanced picture of the impacts of water privatization in the town, Miller worked in a sustained way to record stories from a wide range of perspectives. The result is a nuanced presentation of the complicated struggles the community was facing and what stood in its way in terms of finding solutions. In order to invite people to share their views, Miller worked hard to build trust with community members, spoke at length with them about her goals for the project, and engaged in frequent discussions with individuals and groups (Miller, 2009, p. 63).

Unlike many journalists and documentary makers whose motivations are sometimes mixed, Miller explains that she felt a "professional responsibility" to learn the "full story" (2009, p. 64) of the effects of water privatization in the town. This meant that she committed herself to amplifying different people's perspectives, even though she did not agree with all of them, and to fostering a debate among residents and power brokers. She also recalls her attempts to "avoid fueling the conflict, which sometimes makes for good storytelling but not for dialogue or problem solving" (2009, p. 64).

Miller explains that her approach to participatory filmmaking evolved out of her appreciation for strategies adopted by organizations including Puntos de Encueontro (Puntos), or Meeting Points in English, Witness, and the NFB. Puntos is a group women's rights organization that has worked for approximately 20 years in order to try to stop gender violence. It has produced television dramas and "new media projects" (Miller, 2009, p. 69) that highlight "sexual exploitation and trafficking" throughout the region (Centre for Oral History and Digital Storytelling, n.d.) In order to produce a soap opera in Nicaragua, *Sexto Sentido*, or *Sixth Sense*, as the title is translated in English, and generate discussions about "homophobia, rape, domestic violence, and teen parenting" (Miller, 2009, p. 69). Each time the program was aired, its actors appeared on a radio program in order to solicit feedback from community members. According to Miller, this spurred wider conversations among ordinary citizens about controversial or taboo topics. *Sexto Sentido* has also sought public input about their program, not only to discuss issues that have come up in particular episodes, but to learn how fans would like to see topics represented in the future (Miller, 2009, p. 69).

Miller has incorporated this method in her own filmmaking by showing rough-cuts of her projects to individuals and groups she has filmed. Screening early versions of *The Water Front* (2007) with people and organizations in Highland Park allowed Miller to hear what they appreciated as well as their concerns. Miller reports that some residents suggested the documentary highlighted too many "negative aspects of the community and not enough of the city's accomplished past" (2009, p. 74-75). She states that others felt that she should have given more space in the film in order to amplify the voices of the elected officials. Although Miller chose to make changes to the film based on the feedback she received, she explains that she kept editorial control of the project. She refers to media artist jesikah maria ross, who came up with the expression "a continuum of functional participation" (qtd. in Miller, 2009, p. 72). Miller indicates that although community members may be interested in collaborating on projects, their life circumstances and resources often affect the degree to which they can be involved. Taking this into consideration, Miller approaches her collaborations with community members in a way that is democratic, practical, and allows her to not abandon her role as a filmmaker and researcher.

Miller's decade-long experience working with Witness, a non-profit organization based in New York, which supports people around the globe in documenting human rights abuses, also influences her approach to filmmaking. The aim of the organization is to assist individuals and groups who are immediately affected by rights violations and to help them create change. Miller claims that reflecting on Witness's philosophical allowed her to shift her stance from making films about issues, such as water privatization, to making projects that "strengthen alliances

between groups working around race, poverty, and the environment" (2009, p. 69). She adds that rather than trying to get her films seen by the greatest number of people, by adopting a strategy similar to the one that Witness practices, she makes it a priority to ensure that her films are viewed by people who have the ability to make a difference. In the case of *The Water Front* (2007), this meant it was crucial for Miller that city councillors who had the power to make decisions about water privatization watched the documentary.

# **Challenge** for Change

Literature on participatory documentary filmmaking with marginalized communities, primarily in Canada, significantly influenced the philosophical direction of this project and the methods that my collaborators and I adopted. CFC/SN was one of the world's most ground-breaking and wide scale participatory documentary initiatives. The program was launched by the NFB in 1967 in conjunction with a number of other governmental agencies. Over the next 13 years, it produced 145 English-language and 60 French-language films. Its goal was not only to make film and video projects, but to generate awareness and support social change in relation to a number of issues, including poverty, women's rights, and conditions facing First Nations communities. Although many Canadians had benefited from economic growth, inequality and poverty were prevalent, and few citizens were aware of the struggles that disenfranchised communities faced (Moore, 1987, p. 48). The CFC/SN purposefully involved communities in production processes and incorporated their responses in the films that they made (Waugh, Baker, & Winton, 2010, p. 4) in an attempt to address these issues.

One of the most influential programs created under the CFC/SN umbrella was a series of mini-documentaries filmed on Fogo Island, Newfoundland. Local communities had been facing difficult socio-economic conditions created by fishing companies that restricted people's abilities to earn adequate livelihoods. The Newfoundland government was planning to relocate the island's 5,000 residents and many of them were opposed to these plans (Marchessault, 1995, p. 357). Colin Low, one of the CFC/SN founders, writes: [We] used film as a catalyst to generate local debate — to give local people a voice and even editorial control — and to provide these people with access to people in power, via film" (1984, p. 17). By adopting a participatory methodology, the filmmakers empowered local residents to resist decision makers' plans, and many were able to remain in their communities rather than being displaced (NFB, n.d.)

Another notable CFC/SN project, *VTR St-Jacques* (NFB & Sherr Klein, 1969), focused on an economically disadvantaged neighbourhood of Montreal that had been neglected by successive governments. Residents were frustrated by consistently negative and stigmatizing journalism coverage of their community. In 1969, the NFB supported a group of active citizens in the area by training them to use using 16 mm cameras and edit film. Local residents reported that telling their own stories and organizing local screenings was a productive way of informing people about the issues they were facing (Hénaut & Sherr Klein, 1969).

In spite of its stated intentions, the films produced by the CFC/SN did not lead to significant social change, because the power that officials at the NFB and in government held was not adequately questioned and countered. Marchesseault explains that it was not always clear whether individual films reflected the interests of people in power or those of ordinary and affected citizens (1995, p. 77). Although Marchesseault recognizes that media makers and participants are able to use technology to address power imbalances and support social change, she insists it is vital to consider the nature of the dynamics that are formed with between media producers and communities (1995, p. 77).

In developing this project, I explored a number of other participatory documentary initiatives produced in a range of media in recent years aimed at challenging hegemonic narratives and creating social change. These efforts include photography projects in Rio de Janeiro that were designed to produce counter-narratives about favela life (Baroni and Mayr, 2017). I also explored *Homeless Nation* (Aung-Thwin, Cross, & Gaylor, 2003), a participatory and interactive project that was produced by Daniel Cross and EyeSteel Film, which provided opportunities for street-involved people in Montreal to create personal narratives in the form of text-based, audio, and video testimonials (Homeless Nation, 2002, p. 3). Cross views these stories as "unique first person stories from the street" that have the potential to "break-down" any "stereotypes" (qtd. in Homeless Nation 2003, p. 6) about this particular population. He was also determined to develop a "national collective voice" and "create dialogue between Canada's homeless and mainstream society" (qtd. in Homeless Nation, 2002, p. 6). Cross hoped this could help "save people's lives" (qtd. in Homeless Nation, 2002, p. 4) and claimed that having access to a communication platform could help prevent people from going missing from the country's streets, as they had in Vancouver's DTES where serial killer Robert Pickton had abducted and murdered dozens of women.

Like the residents of Fogo Island, Saint-Jacques, and other communities that have faced challenging social and economic conditions and were involved in CFC/SN films and other participatory projects, people directly and indirectly affected by the opioid crisis have been largely silenced. My intention in this project was to use participatory methods in order to disrupt these silences, generate wider discussion, and encourage social change. Yet, working in participatory ways raises many ethical and methodological questions that often challenge producers, researchers, and collaborators and require significant foresight and discussion, as I discovered. One of the central questions in the literature on participatory documentary focuses on who holds the authority to make creative decisions, particularly during editing stages.

At the beginning of the study, I indicated in discussions with my collaborators and in the information and consent form that I provided them that I considered working in a participatory manner critical to the project. I indicated that I was aware that they had already endured tremendous challenges related to Michael's passing, and I stated that I wanted to minimize the risk of negatively impacting them in any way. In short, I was not prepared to represent them in ways that they were not comfortable with. Therefore, I assured my interlocutors that I would never object to any of their requests to edit or remove any content that they did not approve from the final project. At the same time, I indicated that I would have the final say on these matters. Yet, even as I articulated my position, the inherent contradiction in my messages did not feel right to me.

As months passed and our work together intensified, my thoughts on the subject of sharing authority shifted. I found myself engrossed by the process of speaking with my collaborators about their memories of Michael and the emotional implications of his death. I felt humbled listening to my interlocutors and appreciated their willingness to speak openly with me. Through the process of constructing their testimonies, listening to their recordings, responding to them, and engaging in further discussions, I developed a profound sense of trust and respect for the participants. The processes we engaged in and the rapport we developed, along with literature on participatory documentary, led me to shift my position on sharing authority. As I write in Chapter 5, I concluded that I could not purport to be truly assisting my collaborators in communicating some of their deepest and most personal stories if, at the end of the day, I was prepared to hold the balance of power and determine the final content of the digital memorial. I became increasingly inspired by Low's vision of how directors associated with CFC/SN were encouraged to conduct themselves. In summarizing Low's perspective, Dorothy Todd Hénaut

(1969) explains that the filmmaker's role is to contribute her or his skills in order to assist communities in expressing themselves. This is a very different approach than directors often take by communicating their personal and creative visions in documentary projects.

Trinh T. Minh-ha argues that unless filmmakers question their own authority, their projects can perpetuate social inequalities and injustices (1990, p. 83). I considered these words and reflected on what I was trying to achieve with this study. I recognized that my initial thoughts about the need to maintain a veto regarding decisions about content were formed to a large degree by reading what Cizek states about her own creative process. Cizek is a Canadian transmedia director who has adapted participatory methods developed by CFC/SN in her work with the NFB for nearly 15 years. She explains that on certain projects, she has maintained "100 percent editorial control over the work" (qtd. in Miller, 2010, p. 430), because she was not willing to compromise her expertise as a filmmaker. Cizek recalls her method while creating I Was Here (2005) with the NFB. It was an online photography-based and installation project about women with young children who have experienced homelessness. Cizek explains that she did not work in fully participatory ways and that she kept editorial control. She states: "I defend that decision because I think that the exhibit spoke very loudly and really moved people in a way that I'm not sure it would have if we had just let each woman choose her photos - it would not have been as strong" (qtd. in Miller, 2010, p. 432). Like Cizek, I initially thought that keeping a balance of power would help me to ensure that the project would fulfil as much of its creative and scholarly potential as possible. This was important to me, because I was motivated to resist dominant narratives about the opioid crisis and people who experience fatal overdoses.

As I read more about CFC/SN, I learned that the debate about sharing authority also took place among filmmakers who were connected to it. Some were not immediately willing to change their traditional ways of working and collaborate in democratic ways with people. As I read more about CFC/SN, it became increasingly important for me to create genuinely participatory conditions with my interlocutors. I considered how CFC/SN film crews working on Fogo Island assured local communities that they would not publish any footage unless it was approved by village residents, and that all unapproved footage would be discarded (Moore, 1987, p. 85). For Low (1984), it was important that anyone who appeared in CFC/SN films had the right to choose how they were presented. As my position on the subject changed, I let my collaborators know, and I found that our professional bonds seemed to strengthen. The content of their testimonies also appeared to get even more personal and compelling. As we moved forward together and they curated and edited their recordings, I became increasingly comfortable with my role as a facilitator and researcher, as opposed to that of a director.

My experiences taking part in two week-long training sessions in 2012 and 2013 at the Story Center, formerly the Center for Digital Storytelling, in Berkeley, CA, also influenced my choice to adopt a more participatory approach. Over 20 years ago, the organization's director, Joe Lambert (2013), developed a method of assisting people who are not professionally trained media producers to create multimedia stories about social issues and advocate for change. During my training at the Story Center, where I learned to produce digital stories and facilitate workshops incorporating this particular method, facilitators emphasized that the priority must be on process. By focusing on methods as opposed to trying to create polished, broadcast-quality narratives, participants of digital storytelling workshops have the freedom to reflect on their personal experiences, express emotions, and develop agency. In order to work in this way, participants must be assured they have "the right to tell [their] story the way [they] want, within the limits of the workshop" (StoryCenter, n.d.).

Beyond ensuring that participants have opportunities to censor their content, Sandra Gaudenzi argues it is crucial that media makers create opportunities for collaborators to be fully involved in planning and producing projects (2014, p. 130-131). I consistently asked my collaborators to share their thoughts about our work, and our approaches were influenced by their feedback. For example, the participants insisted that we keep the project focused on their testimonies and experiences, and that we not invite others to take part, as I outline in Chapter 5.

Filmmakers associated with the CFC/SN emphasize the value of holding test screenings and often modified their films in response to audience feedback (Dansereau, 1968, p. 26). Learning about this prompted me to ask my collaborators if they were interested in inviting a small group of people to listen to their testimonies before we published the digital memorial online. I suggested that the purpose of doing so could be to get a sense of how their narratives were received and understood, and then potentially make changes before we made the project available to the public. My interlocutors were all in favour of this. As I outline in Chapter 5, they identified a number of individuals who were friends and students of Michael's. I sent them digital files of the participants' recordings, and they shared some of their thoughts and feelings with us, specifying that no changes were needed.

When it came to dissemination strategies, I worked closely with my collaborators to develop a plan. The NFB hired projectionists to take the CFC/SN films to citizens across Canada

(Winton & Garrison, 2010, p. 410). Audiences were encouraged to respond to the films in order to generate a "two-way flow of information between government and citizen" (Druick, 2007, p. 81). Today, the possibilities for dissemination are limitless, yet media activists and makers rarely think enough about how they will share their work with viewers. In spite of the range of options available, most media producers remain focused on dominant modes of dissemination, namely working with Hollywood and commercial venues, even though these strategies are no longer relevant for most filmmakers (Winton and Garrison, 2010, p. 405). Winton and Garrison argue that "grassroots/community documentary distribution and exhibition, or counterpublic spaces" (2010, p. 404) should be considered. Some possibilities include "film festivals, film clubs, non-profit indy theatres, café screenings, advocacy series, radical film nights, activist conferences, cinema collectives and campus groups" (Winton and Garrison, 2010, p. 406). Adopting innovative dissemination strategies can help generate discussion and inspire people to take action.

# **Creating an online project**

Producing an online project was of interest to me, because I recognized that doing so could allow my collaborators and I to reach wider publics. In spite of the advantages of working online, there are many challenges that I had to consider.

The internet has allowed many people who were previously unable to take part in media production to do so, either as individuals or in groups (Benkler, 2006). This applied to my project, given that the three participants and I were spread out across the continent. William Uricchio refers to this development as the "digital turn" (2008, p. 102), and writes it has also allowed vast numbers of people to express their points of view that often conflict with others' on the internet. My collaborators and I were intentional about working in ways that allowed us to produce narratives differently than those that are often published and disseminated by major news organizations. However, Zoë Druick is critical of the "digital turn." She argues that the original emphasis of participatory filmmaking as it was first practiced in the 1960s was to counter narratives created by corporate media organizations (2007, p. 121). She claims that in today's digital era, participation does not necessarily translate into meaningful action, and that many contemporary projects are not designed to challenge dominant modes of storytelling.

Similarly, Kate Nash insists when it comes to emerging forms of online and interactive projects, amplifying participants' voices does not necessarily lead to achieving wider social goals

(2014, p. 385). Miller and Allor suggest that producers who create digital media projects with the intention of affecting change must take a number of challenges into account (2016, p. 4). One of these issues is that countless media professionals and non-professional media producers are creating online content. As a result, it is harder than ever to generate interest about virtual projects. For all that has been claimed about the "democratization of memory," because of the creation and accessibility of online archives (Garde-Hansen, 2011, p. 51), powerful corporations such as Google and Facebook continue to curate online content in relatively opaque ways. Although media producers have the option of utilizing search engine optimization tools, it is never guaranteed that once their projects are archived on the internet they will be easily found by masses of people. Therefore, it can be helpful to develop projects on a range of platforms. Also, participatory filmmakers must contend with the fact that most users stay on individual websites for just five minutes, and only a quarter of visitors return a second time (Epstein and Knowlton, 2015, p. 2).

#### **Digital memorialization**

Commemorative practices have been established around the world for centuries. Rapid advancements and increasing access to digital technology have allowed many people to remember loved ones as individuals and in collective ways. Recent and emerging practices in this area have created opportunities for bereaved people to memorialize decedents on the internet in ways that not long ago were primarily restricted for privileged white men in the West.

The purpose of memorials is to support people who are grieving, allow them to pay tribute to those who have died, and enable them to share their personal feelings. Memorials are intended to be a lasting space where survivors are able to "connect emotionally and spiritually with their loss" (Veale, 2004, p. 2).) Memorials also give the bereaved opportunities to communicate how the deceased affected their lives. According to Kirsten McAllister, by creating memorials, people make records of significant parts of the lives of people who have passed away (2010, p. 100). She adds that memorials encourage visitors to take time to consider how individuals who have died have impacted their loved ones and society. Individuals who produce memorials communicate that the deceased are worthy of being remembered, not only in the present but for years to come, because of the contributions they made during their lifetimes. In this sense, individuals who are commemorated live on in the minds of the memorials' creators' and the public's imagination.

Commemorative practices undertaken by friends and family are quite different from public forms of memorialization. In recent years, organizations have created virtual memorials in order to honour people who have died in terror attack, acts of mass violence, and other events. These memorials tend to communicate "official" responses (Hess, 2007, p. 815). For example, virtual memorials were produced following the mass-shooting at Virginia Polytechnic Institute in 2007 (Virginia Tech. We Remember, n.d.), after attacks that killed 144 children and adults at a school in Peshawar, Pakistan in 2014 (Dawn, 2008), and to pay tribute to police in the UK who have died while working (Police Arboretum Memorial Trust, 2018). Other digital memorials have been built in response to historical events such as the deaths of UN personnel (United Nations, n.d.), the 1994 genocide in Rwanda (Kigali Genocide Memorial, 2015), the Korean War (Korean War Legacy Foundation, n.d.), and the First World War (Imperial War Museums).

These memorials reflect official views, however, in the hands of individuals who want to honour loved ones who have died, digital technology becomes a democratizing tool (Garde-Henson, 2011b, p. 70). Before access to digital technology and the internet became widely available in the West in the late 1980s and 1990s, people typically shared news about family members' death by paying to publish death notices in local or national newspapers, however, the costs of doing so were prohibitive for many communities. Obituary practices have traditionally been even more exclusionary and elitist<sup>13</sup>. Editors, writers, and owners of journalism organizations, who until recently made the bulk of decisions about who was worthy of memorialization in newspapers, were predominantly male (Fowler, 2007; Ogletree, Figueroa, & Pena, 2005). These publications predominantly reserved space in their obituary pages for tributes to influential, wealthy, white men and other privileged individuals whose achievements publishers considered consequential (Fowler, 2007; Moremen & Cradduck, 1998-99; Moore, 2002). Women (Roder, Kirchler, & Hölzl, 2001; Moremen & Cradduck, 1999; Tight, 2008) and members of minority cultural and social groups, including Aboriginal women in Canada (Jiwani, 2016), were largely excluded from obituaries.

Marginalized communities, including racialized groups, people who lack significant financial resources, individuals of different abilities, sexual minorities, and migrants are increasingly choosing to remember people who have died outside of mainstream journalism publications (Cultural Memory Group, 2006; de Vries & Rutherford, 2004; Hladki, 2014; Jiwani,

<sup>&</sup>lt;sup>13</sup> I am grateful to my PhD supervisor, Professor Yasmin Jiwani, for sharing her research on evolving obituary and grieving practices in the digital environment. I draw heavily from the work that she has conducted in this section.

2006, 2016). The growing number of cyber memorials means that newspapers are no longer the sole and most influential space for reporting deaths.

Technology allows individuals from many sectors of society to develop agency by memorializing in their own ways online (Foot, Warnic, & Schneider, 2006). Pierre Nora claims that the "democratization of history" (2002, p. 8) can only take place when disenfranchised and minority communities are able to express their identities on their own terms. He argues: "Unlike history which has always been in the hands of the public authorities, of scholars and specialised peer groups, memory has acquired all the new privileges and prestige of a popular movement" (2002, p. 6). Ordinary citizens using the internet to create virtual memorials often do so as a means of archiving and sharing their own memories and perspectives about incidents that affect wider populations.

Virtual memorials created by everyday people tend to be less sophisticated than those produced by institutions and organizations. This is because individuals are generally less techsavvy and have fewer resources (Hamill, 2009, p. 119). However, social media platforms such as Facebook and MySpace have made it easier for users to create 'R.I.P' (rest in peace) memorial pages (Brubaker & Dourish, 2013; Karppi, 2013; McEwen & Scheaffer, 2013; Ryan, 2008). Individuals also frequently produce and publish digital memorials on Vlogs and YouTube (Harju, 2015; Gibson, 2016). What they lack in sophistication, they make up in personalization. With digital technology, people can create nuanced and humanizing narratives about individuals who have died.

In contrast to physical memorials, digital memorials are relatively affordable, can remain on the internet indefinitely, and do not need to be maintained (Ryle, 2002). They can also be modified or adapted, as some creators have chosen to do, on the anniversary of people's deaths or at other times. Doing so allows bereaved people to continue to communicate with the dead and process their grief. Virtual memorials often invite others to take part in acts of grieving by sharing "their sympathy and consolation" (Metcalf & Huntington, 1999, p. 54). According to Jay Ruby (1995), memorials allow people to simultaneously acknowledge the death of people they cared about while also preserving their memory. It is becoming more common for people to view digital memorials as a way for the living to maintain connections with those who have died (Hallem & Hockey, 2001). Jed Brubaker and Janet Vertesi claim that virtual memorialization allows decedents' profiles "to remain active" (2010, p. 3) for lengthy periods of time. Memorializing online allows bereaved people not only to continue to engage with individuals who have passed away, but to also build connections with others who are affected by their deaths (Church, 2013; Woodthorpe, 2011; Roberts 2004). Other scholars write that digital memorials enable people who are grieving to delay their full acceptance of loved ones' deaths (Lagerkvist, 2013; Walter, Hourizi, Moncur, & Pitsillides, 2012). Also, online memorials can be accessed by people from practically any location where internet signals are available (Veale, 2004, p. 9). Lindsay Marshall (2001) claims that people who produce virtual memorials often feel satisfied knowing their writing or creations can reach people across the globe.

Digital memorialization enhances the capacity for more people to take part in remembering and participating in death rituals (Bennett & Huberman, 2015; Graham, Arnold, Kohn, & Gibbs, 2015). It allows people to "cop[e] with grief and loss" (Veale, 2004, p. 3) and "to recover from their grief by providing a pleasant 'memory picture'" (Metcalf & Huntington, 1991, p. 54). Virtual memorials also create opportunities for people to remember individuals who have died in public spaces that are open to others to enter and leave at all times (Hallam & Hockey, 2001, p. 61).

According to Hess (2007), digital memorials created by private citizens have reflected a wide range of responses to significant events and have challenged the way institutions have attempted to control public narratives. Ekarina Haskins insists that digital memorials help people resist "hegemonic official memory" (2007, p. 403), because multiple producers with varied perspectives can create them collaboratively. She argues: "Instead of only official accounts disseminated by mainstream media and the government, all kinds of stories can now become part of an evolving patchwork of public memory" (2007, p. 405). This perspective echoes Michel Foucault (1972), who writes that historical narratives often gloss over various individuals' and groups' experiences. He asserts that different points of view about events and experiences are needed.

Increasing public participation in digital memorialization is taking place within the context of what Jacques Derrida describes as "archive fever" (1996, p. 71). For Derrida, the fever is characterized by a movement, not only by everyday citizens, but by "museums, broadcasters, public institutions, [and] private companies" (1996, p. 71) to produce digital archives as part of a wider effort to store information in order to mitigate the risk of its loss. Some of the most common archiving activities include producing online memorials, taking photographs, creating digital shrines, as well as "online museums, alumni websites, broadcasters" online archives, fan sites, online video archives and more" (Garde-Hansen, 2011, p. 71).

Scholars have written about communities coming together to produce digital memorials. In these instances, the internet can be viewed as a "collective memorial landscape" (Veale, 2004, p. 11). People who engage in virtual memorialization effectively produce "acts of cultural memory" (Veale, 2004, p. 11) that defy hegemonic representations found in dominant media. When memorials are produced in collaborative ways, survivors can also gather together on the internet, as opposed to creating projects in isolation, and participate in memorializing the deceased (Church, 2013; Savoie, 2010).

One particular digital memorial that was collaboratively produced and inspired me to conduct this project was created for Philando Castille, a 32-year-old nutrition supervisor at an elementary school in St. Paul, Minnesota (Pollen Studio, n.d.). Castille was shot by a police officer in his car seven times, while reaching for his identification. His partner Diamond Reynolds and four-year-old daughter were in the vehicle at the time, and Reynolds posted footage of the aftermath of the killing on her Facebook page in real time. Twenty-five artists mostly from Minneapolis and St. Paul produced the virtual memorial for Castille using a combination of images, creative writing, and publishing this content in an interactive format. Their goal was to raise awareness about his killing and speak out about the violence. They refer to the project as "a community portrait of grief, protest, power and love" (Pollen Studio, n.d.).

The growing number of scholarly sources on digital memorialization, including those highlighted in this chapter, is indicative of the recent and ongoing proliferation of the phenomenon. However, little is known about how families and communities impacted by fatal drug overdoses are utilizing the internet to grieve and remember lost loved ones. My study fills a gap in the literature by exploring how three individuals who were intimately and closely connected to an individual who died from a drug-related overdose have come together to commemorate him through this medium. By publicly revealing details about Michael's death and his bipolar disorder, and by sharing nuanced information about his life, my collaborators are resisting the control of influential journalism organizations. They are countering the power that the gatekeepers of newspaper obituaries use in order to silence the effects of the opioid crisis by rendering those whose lives are shattered invisible.

Despite its potential to empower ordinary people suffering from grief, it is important to briefly consider a number of ethical and methodological challenges associated with digital memorialization. Producers must consider who owns and controls the archive, who can contribute to it, and whether there are other restrictions in terms of the number of people

involved (Derrida, 1996; Garde-Hensen, 2011b, p. 71). Another issue to be mindful of is what visitors to digital memorials can potentially do with material that has been posted online, because there are risks that content can be re-appropriated by people with sinister intentions. Although digital memorialization has created opportunities for more individuals to publicly remember people who have died, not everyone has equal opportunities, the same resources, skills, or time to take part in initiatives like this. Additionally, Haskins writes that the internet is contributing to an information and memory glut, because an unprecedented amount of content and memories are being stored online (2007, p. 407). One of the potential consequences is that publics could develop historical amnesia and overlook important issues, a concern that I discuss in greater depth in Chapter 5.

#### **Counter-memorialization**

Official memorials are often constructed in order to communicate official or dominant ideologies. As a result, they often fail to articulate a diverse range of experiences and perspectives. Counter-memorials are created with the goal of disrupting established and prevailing narratives and memory by amplifying a multiplicity of views. This project has been inspired by a number of counter-memorials that I highlight in Chapter 2. They were created in response to the Air India disaster, violence against women, murdered and missing women, the Holocaust, and human rights violations in the Occupied Palestinian Territories. Many of their scholar-producers have been motivated to challenge hegemonic narratives and memory and encourage greater inclusivity and representation of diverse groups and communities. But what distinguishes counter-memorials from traditional memorials?

James Young writes that physical memorials are often built with stone in order to communicate an illusion of permanence (1992, p. 267). Scholars have argued that historical narratives communicated through memorials are often linear constructs that are imposed on societies and obscure individual and localized experiences (White, 1981). Christine Bold, Ric Knowles, and Belinda Leach insist that memorials can be a form of social control that promote "active forgetting" (2002, p. 127-128). They claim that many memorials have failed to adequately represent the experiences and voices of key groups of people. Alan Gordon suggests that power relations play a significant role in the production of memorials and the construction of public memory (2001, p. 4). For example, he claims that official monuments in Montreal have prioritized the historical experiences of English and French-speaking communities. Meanwhile, he insists that other groups in the city have yet to be represented through similar initiatives. Scholars have argued that across the globe, memorial monuments have silenced groups that are not considered dominant in their own societies. This is often a deliberate, repressive, and violent eradication of the histories of populations that are viewed as adversaries of the state (Connerton, 2008, p. 60).

Suanne Ware argues that memorials should not be viewed as "pure or complete" (2008, p. 62), and suggests they must be reconsidered and challenged, because memory is never fixed. Young claims that governments and institutions attempt to create memories, but countermemorials invite societies to question these efforts and the hegemonic narratives that are often associated with them (1988, p. 855). He adds that unlike physical memorials that are often unchangeable, counter-memorials must be adaptable, malleable, and even designed to vanish. Their producers deliberately construct these projects in the same environments in which historical narratives and memory have been established. Echoing Foucault (1994), Ann Burlein argues that this juxtaposition is essential in order to "contest, break open and cut" (1999, p. 217-218) dominant narratives and memory.

Governments in Canada will likely never erect monuments to those who have died from drug-related overdoses. To do so would mean acknowledging inadequacies in their responses to the crisis. Frustration with the federal government's lack of action was evident on May 14, 2017, when Canada's former health minister, Jane Philpott, addressed a crowd of harm reduction researchers, activists, and people who use drugs at the International Harm Reduction Conference in Montreal. As she spoke, a number of individuals stood up, turned their backs to the minister, and held up banners with words such as #TheyTalkWeDie. They posted similar messages on social media platforms including Facebook and Twitter (McClelland & Dodd, 2017).

The counter-memorial that I created with my collaborators is an effort to pay tribute to Michael. It is also intended to illustrate that it is possible to remember individuals who experience fatal drug-related overdoses in ways that are rarely communicated by authorities and dominant journalism organizations. The project also aims to communicate to policy makers that more must be done to prevent others from needlessly dying from overdoses. The participants are expressing this message through their testimonies and the digital memorial that we created together. Like me, they do not anticipate that the project will lead to policy change, but we hope it will add to the conversation about the need for more early intervention programs for people with mental illness.

# Witnessing

In order to support my collaborators in producing their testimonies and the digital memorial, as outlined above, as time passed, I increasingly saw my role as that of a facilitator. I concluded that I did not feel it was appropriate for me to make choices about the final content for the digital memorial. I was more interested in working with participants and making decisions together. I wanted to learn who they were as people and their experiences by asking questions, listening closely, showing empathy, and being a witness. Having a year to engage in these processes enabled me to assist my interlocutors in producing counter-narratives. I was familiar with the concept of witnessing in Buddhist meditation and yoga. The late American Zen Buddhism teacher and peace activist Bernie Glassman insisted that "we can't heal ourselves or other people unless we bear witness" (2013, p. 76). According to Glassman, by being aware of "the unfolding of our daily lives, not shrinking from any situation that arises, we learn. We open to what is. And in that process, a healing arises" (2013, p. 37).

I also wanted to explore how humanities scholars have defined and written about witnessing in order to learn to apply these tactics in this study. According to John Peters, witnessing involves the act of observing and communicating elements of what has been seen to an outside person or group (2008, p. 709). It also allows those who receive information to adopt a moral position and take action (Peters, 2008, p. 721). Witnessing also calls on people to consider their emotional and political responses while learning about distant people who are suffering (Boltanski, 1999, p. 11; Chouliaraki, 2006, p. 123). It is an appropriate method for this study, because although a growing number of people are directly or indirectly affected by the opioid overdose crisis, many still believe it is happening to others. If we are going to find solutions and prevent further suffering, it will require more people to understand what individuals have experienced and how they have personally suffered.

Annette Wieviorka (2006) has dubbed the current historical period "the era of the witness," because of the vast number of people who have produced personal testimonies about a range of critical events and issues. Some of the most recognizable witnesses who wrote about their experiences of 20<sup>th</sup> century events—especially World War II—include Vaclav Havel, Jacobo Timerman, Rigoberta Menchu, Martin Luther King, Nelson Mandela, and Aung San Suu

Kyi<sup>14</sup>. All of these individuals served time in prison for their commitment to witnessing oppression. Elie Wiesel, Anne Frank, and Primo Levi are among the best-known writers who documented their experiences during the Holocaust. Peters insists that those who personally bear witness to injustices often claim a moral position and their testimonies can challenge evil or powerful actors. He claims: "To witness [is] to be on the right side" (2008, p. 714). Those who read their work are able to witness critical parts of the writers' lives, albeit from a distance.

Reiterating what Wiesel and other Holocaust survivors and scholars have written, Sue Tait claims that once people have witnessed injustice and suffering, they are obliged to respond through testimony (2011, p. 1221). Also reflecting on Wiesel, Peters writes: "Already having cheated death, the survivor seeks to save his experience for others who can never have them" (2008, p. 714-715). Barbie Zelizer (1999) also argues the witness has a duty to speak out. Today, reporters such as Lynsey Addario, Nicholas Kristof, citizen journalists in countries like Syria, as well as activists and members of human rights organizations, are committed to bearing witness to conflict, rights abuses, and other injustices.

Witnessing was critical in terms of enabling me to learn what my collaborators had been through. Throughout the weeks and months following Michael's death, I frequently observed my interlocutors as closely as possible. In listening, posing questions, and engaging in dialogue with them, I was able to develop a sense of the profound nature of their losses. I gained insights into the emotional and psychological challenges that Michael's passing created for them. I never attempted to change their experiences, even when confusion, sadness, longing, and other emotions presented themselves. My background in meditation allowed me to accept what I observed and recognize that it would evolve. By serving as a witness, I think I was able to help create an environment in which the participants felt secure enough to share their personal testimonies, knowing that I would help share their stories with others in a way that they felt comfortable with.

# **Reflexive anthropology: Accepting emotions**

Anthropologists have traditionally prioritized the use of the authoritative and distanced voice in scholarly writing. Pratt argues that writing focused on researchers' own experiences has

<sup>&</sup>lt;sup>14</sup> In spite of her commitment to speaking out about human rights in Myanmar, which led to her decades-long house imprisonment, Suu Kyi has yet to acknowledge the atrocities committed against the Rohingya people in Myanmar's Rakhine State, which the UN has described as a genocide (AP at the United Nations, 2018).

been largely dismissed as "self-indulgent, tribal, or heretical" (1986, p. 31). In spite of these criticisms, personal narrative has long played a critical and under-appreciated role in ethnographic writing. Scholars have used personal narrative to "anchor" their work in "the intense and authority-giving personal experience of field work" (Pratt, 1986, p. 32). Pratt adds this form of writing is often the most "symbolically and ideologically rich" (1986, p. 32). In spite of its strengths, personal narrative has largely been relegated to introductions or early chapters in which researchers tend to situate themselves in their studies and present their first encounters with research participants, and it seldom appears in their wider texts.

Self-reflexive anthropology, first championed by scholars in the early 1970s, stresses the value of researchers examining and writing about their own experiences and connections to the individuals and communities they research (Rabinow, 2007). In recent years, a number of anthropologists have challenged rigid forms of ethnography and have included first-person accounts in their research. Davies claims that researchers *must* have personal experience with the issues they explore. She describes self-reflexivity as a process of "turning back on oneself" and of "self-reference" (2007, p. 4). Davies argues that scholars need to consider and be transparent about how their involvement in their studies affects the results of their work, especially while conducting "intimate, long-term and multi-stranded" research (2007 p. 4).

Reflexive anthropology requires that scholars be aware of the wider context of research participants' lives and the way their societies function (Davies, 2007, p. 119). In this sense, it was important for me to understand how each of my collaborators viewed the significance of their respective connections with Michael. The bonds that Carina had with Michael were different than those that Rose and Andréa shared with him. I also reflected on whether having regular conversations about personal matters as we did throughout the study was something the participants had previously done. Not everyone in the West is inclined to speak openly about grief, and doing so remains a significant taboo (Aaron, 2013). As noted in the introduction, many people who meditate, including my interlocutors, have had interviews with meditation teachers. Although my discussions with my collaborators were not meant to replicate the format that takes place in meditation settings or on a retreat, the process of "checking in" in a safe and respectful environment was familiar to them, which facilitated the process of creating a personal memorial.

Davies writes that researchers must be aware of power dynamics that can be subtly or clearly felt, because they can influence discussions and the knowledge that is produced (2008, p. 120). As I wrote in the introduction, I made a point of emphasizing to my collaborators that I had

no intention of becoming their spiritual teacher or a replacement for Michael. Communicating this allowed me to conduct myself as a researcher without any other pretenses. I also looked for differences in our social statuses that could potentially influence our connections and the project (Davies, 2007, p. 120). For instance, I was conducting the project as a doctoral student and fulltime university instructor, and they do not have post-graduate degrees. Given the status that academics and people with advanced degrees hold in society, it was important for me to be humble and transparent in my work with my collaborators. As a white male researcher, I never felt that I had any more power than the three participants, but it is important to acknowledge the history of male domination in academia and wider society, and I was mindful of this throughout the project. I tried to reduce any power imbalances between the participants and myself by seeking their input on as many elements of the project as possible, by trying to listen closely to them, and by showing interest in their experiences and views with a sense of compassion and kindness. I felt it was vital to seek their feedback on how the project would ultimately represent Michael (Davies, 2007, p. 121). As noted previously, Carina emphasized that her priority was communicating the relationship between Michael's mental illness, his overdose, and the need for more early intervention programs. This helped me to formulate the questions that I asked Carina, Rose and Andréa, and significantly influenced the direction of the project.

One model of reflexive anthropology that was particularly useful for me comes from Behar, who writes that her willingness to become a "vulnerable observer" (1996, p. 207) in her ethnographic research was inspired by Rosaldo. He approached his fieldwork with a sense of not knowing everything and using his personal experiences to prompt his deeper reflections and discoveries. Rosaldo spent 14 years studying the practice of headhunting among Ilongot people in northern Luzon in the Philippines. It was only when he reflected on his emotional responses to the death of his wife, Michelle Rosaldo, that he was able to comprehend why the Ilongot could bring themselves to behead people. He writes: "My life experience had not as yet provided the means to imagine the rage that can come with devastating loss. Nor could I, therefore, fully appreciate the acute problem of meaning that Ilongots faced in 1974" (1993, p. 168).

In considering the value of Rosaldo's reflexive approach, Behar claims that although it has not been widely acknowledged or appreciated, researchers must give themselves permission to "feel" (1996, p. 207). Rather than encouraging scholars to engage in unnecessary sharing or sentimental work, Rosaldo invites ethnographers to use our their "own feelings as sources of insight" (1993, p. 176). He argues that "emotional intelligence" (1993, p. 172) requires scholars

to avoid conducting themselves in masculine ways that have dominated anthropology and limited researchers. Instead, he invites ethnographers to experience "unmanly states" such as "rage, feebleness, frustration, depression, embarrassment, and passion" (1993, p. 172). Behar adds that reading Rosaldo prompted her to "explore emotional tensions" (1996, p. 209) in her relationships with her research participants, which can often be avoided or glanced over. She argues that self-reflexivity has become a critical component of anthropological research and can be an indication of scholars' commitments to social and political issues (1996, p. 210).

Throughout my life, I have often experienced feelings of anger, devastation, and grief, often in connection to my experiences with my mother. I believe that my willingness to feel these emotions contributed to my sense of being able to witness my collaborators and empathize with them. Throughout the project, being in touch with and accepting my feelings allowed me to feel the reverberations of my collaborators' emotions. Yet, as noted previously, in my early discussions with my collaborators, I mentioned these experiences, but as we moved forward together, I never raised these matters again. In my conversations with my interlocutors, I opted to stay silent about my personal history, and I focused on supporting them in producing their testimonies and the digital memorial. This does not mean that I did not think about my past. However, I concluded that sharing details from my life would not be beneficial for them, because they were dealing with many difficult emotions and circumstances. I was also cautious about potentially influencing the content of their testimonies. McAllister explains she was initially concerned about possibly "imposing" her own "interpretation" (2010, p. 45) on her ethnographic research with Japanese-Canadians who had been interned during World War II in New Denver, B.C. By drawing on Rosaldo and resisting the impulse to "control" (2010, p. 82) her emotional responses, she claims that she was able to feel and document the impacts of her engagement with her collaborators in transformative ways. In spite of my choices to not disclose parts of my past in depth with my interlocutors, I was able to approach the study as a vulnerable scholar, and as I have noted previously, I later adopted an autoethnographic approach, which led me to explore and share parts of my life in this thesis.

There were moments during this project, particularly while having Skype conversations with Rose as she shared her sadness and grief with me, when I had significant emotional responses. I was moved by her testimony and I felt tears to come to the surface. I think the fact that we were both willing to be open to emotions when they arose contributed to a feeling of ease and trust in these discussions. However, I never made my responses and emotions the focus of

our conversations. When my collaborators expressed themselves, I acknowledged what I heard and allowed myself to feel what came up for me in the moment. In doing so, I felt akin to what Clifford Geertz describes when he states, "You don't exactly penetrate another culture . . . You put yourself in its way and it bodes forth and enmeshes you" (1996, p. 44).

Like Behar, McAllister, and Rosaldo, Kamal Al-Solaylee argues that the ethnographer's personal voice and emotions need not be confined to the margins of anthropological texts. He draws on his personal experiences as a man of colour to write about other brown people's experiences. In spite of his admitted privilege as a Canadian citizen and professor, Al-Solaylee writes that his experiences as a brown man enabled him to examine and communicate other people's realities. He claims that by "privileging the brown experience" as his "lens for exploring the world" (2016, p. 25), he is able to write in nuanced ways about migrants, refugees, undocumented workers, Arabs, and Muslim people in the U.S., as well as about other "disenfranchised" (2016, p. 25) people who are often framed as threats. In his book, *Brown* (2016), he describes walking his dog and having his condominium neighbours in Toronto approach him as a domestic worker (2016, p. 13), being racially profiled after the attacks of September 11, 2001 (2016, p. 6), and being called racial slurs while studying in the UK (2016, p. 6). He explains:

The realization that my struggles to feel at ease in the skin I'm in reflect global issues and trends that go beyond the personal. Everywhere I looked, every story I heard, all but confirmed the prejudices and advantages that a skin tone can inflict or bestow on individuals, communities and nations. (2016, p. 10)

Behar questions to what degree scholars should allow themselves to be emotionally affected by people they examine in their studies. She suggests that the researcher's task of documenting the "native point of view . . . without actually going native" (1996, p. 5) seems contradictory. However, there is a danger in researchers over-identifying with the people they study. As Geertz writes, I felt compelled to develop a sense of "close-in contact with far-out lives" (1988, p. 6), and recognized the challenge of doing this. I understood that my collaborators will likely feel the effects of Michael's death in different ways and to varying degrees for the rest of their lives. Since my involvement with the participants and my relationship to Michael's passing was going to be relatively brief, I knew that it would not impact me as much as my

interlocutors. In light of this, I felt it was important, as Behar argues, for me to ensure that my exchanges with the participants did not become overly personal, self-serving, or autobiographical (1996, p. 6-7). This did not mean ignoring my feelings when they arose, and I was able to remain vulnerable and focused on my work as a researcher.

My mother did not use drugs or die of an opioid overdose like Michael tragically did. However, my experiences with her (and in her absence) while she was alive and after her death became an imperfect lens through which I partially related to my collaborators' experiences with Michael. This allowed me to bear witness and support my interlocutors in sharing their stories with an open mind and heart while refraining from interfering in their grief processes.

# **Standpoint theory**

As noted in the introduction, people who have lost loved ones to opioid overdoses have been largely silenced by the pervasive othering of individuals who use drugs and experience fatal overdoses. Feminist theorists have developed and used standpoint theory in order to challenge this type of silencing and suggestions that there are indisputable and objective truths. These scholars insist that it is vital to consider the "social positioning of the social agent" (Stoetzler & Yuval-Davis, 2002, p. 315). According to Marcel Stoetzler and Nira Yuval-Davis, "Hegemonic 'universal' knowledge has tended to ignore and render invisible marginalized experience, imagination, and knowledge" (2002, p. 327). In their words, my interlocutors have "a privileged access to the truth" (2002, p. 315). By speaking from marginalized perspectives, the participants claim agency and produce "*different* insights" (Stoetzler & Yuval-Davis, 2002, p. 319). Their testimonies reflect the "situatedness" of their "knowledge" (Stoetzler & Yuval-Davis, 2002, p. 325) and resist dominant narratives.

Patricia Collins argues that certain groups, including media organizations, are able to make their views "prevail over equally plausible perspectives" (1997, p. 380), not because they are truthful, but because of their power. As a result, she adds that it is understandable that groups of individuals such as the women who participated in this project would be inclined to come together to articulate their personal experiences and resist influential and skewed narratives (p. 380). At the same time, Collins acknowledges that given the history of groups dominating others and invalidating them, some people prefer to remain independent and push back in their own ways (1997, p. 380).

#### Narrative approach and continuing bonds theory

In 1969, Elizabeth Kübler-Ross (1969) developed a model of grieving according to which the bereaved experience denial, anger, bargaining, depression, and acceptance in a sequential manner. Since it was first published, this theory has been widely adopted by grief psychologists and has influenced public thinking. Kübler-Ross argues that prolonged grief can lead people to needlessly suffer and lose a sense of agency. According to Hedtke and Winslade (2016), Kübler-Ross and other grief psychologists have encouraged people who are facing the death of loved ones to get over their grief and return to a state of equilibrium as one might aspire to do after falling ill with a cold or the flu.

Hedtke and Winslade (2016) take issue with Kübler-Ross's formulaic and prescriptive model, and insist that people need to experience grief in their own ways and on their own schedules. They developed a method of narrative psychology that encourages people to create and perform narratives and to freely express their grief. It enables participants to develop confidence and make conscious decisions about their own emotions. Hedtke and Winslade (2016) refer to this process as crafting grief, and insist that it does not require special skills or training, and that it is accessible to virtually anyone. Crafting, as they explain, is deliberately open-ended and involves creative, reflexive inquiry, and storytelling. Drawing on Foucault (1987), Gilles Deleuze (1994), and Jacques Derrida (1976), Hedtke and Winslade (2016) argue that through the narrative approach, people ultimately become different or new in contrast to who they were before the death they are responding to. Unlike traditional grief psychologists, narrative therapists invite people who are grieving to consider exploring ongoing bonds with the deceased. This can be an effective way for individuals to develop agency and express feelings they may still have for those who have died. It also directly refutes Kübler-Ross, because people who explore their continuing bonds with individuals who have died maintain connections with these people that evolve over time.

I was interested in supporting my collaborators in crafting their grief, but I am not a trained as a psychologist. Yet, as I outline in Chapter 4, I believe that experimenting with this method was beneficial for the participants and me as a researcher. I accepted how my collaborators processed their grief, and I never felt it was appropriate for me to encourage them to alter their trajectories. I believe that adopting this method also allowed my interlocutors to produce nuanced and heartfelt representations of the impacts of the opioid crisis on decedents' loved that are seldom communicated by dominant journalism organizations.

## Conclusion

In this chapter, I provided an overview of the scholarly literature that influenced the philosophical orientation of the project. I also discussed ethical and methodological issues related to research-creation, participatory documentary, digital memorialization, counter-memorialization, reflexive anthropology, and the narrative approach and continuing bonds theory.

In Chapter 2, I examine how the case study approach was appropriate for this project. I explore my intention to generate empathy among people who engage with the project for Michael and others who face mental health challenges and may use drugs as a way of managing various forms of pain. I also problematize the notion of encouraging publics to feel empathy, and explore how scholars have examined this issue in testimony research and journalism. I also examine literature focused on counter-memorials and defend my rationale for framing and producing the digital project in this way. I explore two participatory and interactive projects that prioritize audio testimonies as a means of demonstrating the potential of my project to serve as a counter-memorial in the context of the opioid overdose crisis. The chapter highlights a small number of physical counter-memorials that have been created in response to the rising number of drug-related deaths in Vancouver and Australia. I discuss a controversial physical memorial in the U.S. focused on opioid overdoses, and a growing number of online memorials that allow bereaved people to remember individuals who have passed away after consuming illicit drugs. The chapter also features a discussion of other innovative counter-memorials that have been created in response to the Air India disaster, violence against women, murdered and missing women, the Holocaust, and human rights violations in Palestine.

# **CHAPTER 2**

# REMEMBERING MICHAEL STONE: A CASE FOR CREATING A COUNTER-MEMORIAL

# Introduction

This chapter features a discussion about the case study approach and its relevance for my project. By working closely with a small number of people who were intimately and closely connected to Michael, we were able to produce nuanced knowledge about their memories of him and their grief experiences. This information disrupts dominant narratives about the opioid crisis and people who experience fatal overdoses. I also examine my intention to generate empathy among wider publics and highlight how some researchers have been critical of the use of empathy in testimonial research and journalism. Thereafter, I examine how audio testimony has been effectively integrated in digital projects focused on social issues, and argue that doing so in the digital memorial for Michael assists it in becoming a counter-memorial. I also explore physical and digital counter-memorials focused on the opioid crisis and a number of historical events and critical social issues, including the Air India disaster, violence against women, murdered and missing women, the Holocaust, and human rights violations in Palestine.

## **Case study research**

Scholars working in a wide range of fields, such as communication studies, anthropology, sociology, psychology, political science, and economics have used case study research as a method. Many PhD students specializing in a number of areas have also adopted it while producing their doctoral work (Yin, 1989, p. 10). Sharan Merriam explains that qualitative case studies involve "intensive, holistic [research] and analysis of a single instance phenomenon, or social unit" (1998, p. xi-xii). Robert Stake (2005, p. 444) and Sharlene Hesse-Biber add that is a way of thoroughly exploring a case and research results (2017, p. 221). Additionally, Hesse-Biber contends that it enables scholars to develop a "*holistic understanding* of a problem, issue, or phenomenon within its social context" (2017, p. 221). Case study research can involve analysis of single or multiple cases. Many scholars have employed it to probe issues related to collective rights and oppression and injustice (Stake, 2005). Case study researchers have used

multiple methods including "interviews, oral history, ethnography and document analysis" (Hesse-Biber, 2017, p. 221). Regardless of the methods, Stake claims that the primary function of case study research is to develop in-depth knowledge of the perspectives of the people associated with the issue. This appealed to me because, as Stake argues, it promised to enable me to document and help communicate my collaborators' experiences, thoughts, emotions, and memories.

I was keen to investigate the experiences of a small number of people and share nuanced and rich information with wider publics. Hesse-Biber argues that case study research can allow scholars to do precisely that (2017, p. 226). Bent Flyvbjerg (2006) claims that it is a misconception that knowledge produced in studies that explore one or a limited number of cases cannot be applied more broadly. Robert Yin insists that if researchers conduct qualitative case studies in ways that are dependable, credible, and transferable, it can increase the odds that other researchers will value their work. He claims that case study research lends itself to developing "theoretical propositions" (1989, p. 21), as opposed to making sweeping statements about wider populations. Accordingly, the case study methodology suited my purposes, because I set out to illustrate that collaborative testimony and digital memorial production about Michael could allow the project's participants to challenge dominant narratives about the opioid crisis and individuals who experience fatal overdoses.

According to Yin, the words "how" as well as "why" (1989, p. 18) help researchers frame explanatory as opposed to exploratory case study projects. Explanatory projects allow scholars to investigate individuals' or groups' responses to conditions over extended periods. In order to answer the "how" and "why" of Michael's death, this project involved a lengthy process of dialogue, telephone calls, online conversations, email correspondence, testimony recording, participant-observation, and ethnography. The "how" part of my research question informed the methods, including collaborative testimony production and digital memorial production that I engaged in with my interlocutors. These approaches enabled me to assist them in producing counter-narratives.

## **Rationale for creating a counter-memorial**

Justin Trudeau insists his government is doing all it can to address the opioid crisis, but the number of people dying from overdoses continues to rise. Although the Liberal government

decriminalized marijuana, senior public health officials have called on the government to change the law to permit the possession of all drugs, including opioids, for personal use and to increase harm reduction services (CBC News, 2018).

The number of fatal drug-related overdoses has also prompted harm reduction researchers, activists, and loved ones of people who have died to resist taboos and speak out in public spaces, including in obituaries, on social media, in street protests, and through a small but growing number of counter-memorials. The relative lack of public memorialization of people who have died from drug-related overdoses and the urgency that my collaborators and I felt about the need for more early intervention programs for people with mental health issues contributed to my decision to frame this project as a counter-memorial.

Maureen Burns (2002) argues that people who create documentaries communicate in public ways. She adds that ideas expressed in these kinds of projects affect the way people view and discuss issues and therefore contribute to public memory. Counter-memorials function in a similar way. They are designed to facilitate "vernacular interpretations of history" (Hess 2007b, 829), as well as decentralize and democratize public memory.

Counter-memorials are typically produced by ordinary people as opposed to elite or people in power. They involve the tactical humanization of people who have lost their lives as opposed to the communication and perpetuation of dominant ideologies or politics (Longhofer, Floersch, & Hartmann, 2017). Counter-memorials have the potential to resist and shape cultural memory, which Marita Sturken defines as "the memory landscape that we inhabit" (1999, p. 234). She defines this as "a complex mix of narrative, displacement shared testimony, popular culture, rumour, fantasy, and collective desire" (1999, p. 234) that are "entangled with cultural products and imbued with cultural meaning" (1999, p. 3). Those who create counter-memorials are often motivated to resist what Bold, Knowles, and Leach call "active forgetting" (2002, p. 127). They describe this as efforts to silence alternate views and experiences by normalizing narratives that are taught, shared, and accepted as "normal" (2002, p. 127).

Young argues that instead of allowing ordinary citizens to remember in ways that can influence public memory, official memorials often dislocate memory from people's thinking (1993, p. 272). Furthermore, according to Young, official memorials tend to engage the public merely as "passive spectators" (1993, p. 274). He claims that counter-memorials are deliberately oppositional, aim to amplify narratives of people whose stories have been suppressed, and involve these individuals in memorializing processes (1993, p. 274). Caffyn Kelley suggests that

in order for counter-monuments to have widespread effect, they must incorporate a diversity of unique perspectives (1995, p. 10). Bold, Knowles, and Leach insist that in contrast to dominant forms of memory that promote the erasure of individuals' and groups' histories, countermemorials can encourage people to actively remember (2002, p. 127). They add that remembering the past has the potential to enable people to create positive change about critical issues.

In spite of the affordances of counter-memorials, those who plan and build them often grapple with a host of issues. These questions include: How can memorials communicate the individual circumstances of violent occurrences as well as the systemic nature of problems? How can creators prevent memorials from blending into the environments in which they are situated? How can memorials invite participation from a range of collaborators without being adversely affected by internal tensions? How can producers respect the privacy of those who are memorialized in their efforts to affect change? How can counter-memorials help educate the public and decision makers about challenging issues without glossing over difficult details or depleting narratives of tensions (Bold, Castaldi, Knowles, McConnell, & Schincariol, 2007, p. 7). Bold, Knowles, and Leach ask whether actively remembering what has been systematically silenced allows people to find a sense of peace, ease, and "closure" (2002, p. 131). Does creating and disseminating testimonies produced as part of counter-memorials help diminish the influence of problematic narratives? How can narratives produced by marginalized individuals who take part in counter-memorial projects shape wider discourse, public and cultural memory?

Ann Burlein asserts that by reconfiguring dominant ideas and rhetoric in new and innovative ways, thoughts and arguments that are largely viewed as oppositional can become conventional or popular (1999, p. 219). By producing nuanced and heartfelt testimonies about Michael and their connections to him, my collaborators have constructed unique narratives that challenge problematic and common depictions of opioid users and individuals who experience overdoses. By engaging individuals from "informal areas" (Gordon, 2001, p. 6), my goal was to support the participants in contributing to Jürgen Habermas' (1998) notion of the "public sphere." By assisting them in creating knowledge in the present, their memories and experiences of grief related to Michael are able to affect public and cultural memory.

According to Aaron Hess, interactivity can support people who use digital memorials to actively engage in creating memories. Interactivity refers to how users "can interact" with webbased projects by "entering information" that affects the way media content is presented (Hess,

2007a, p. 340-341). Users can also "navigate their way through displays of data and story environments, or they can activate story elements and trigger possible follow-ups" (Uricchio, Woolozin, Bui, Tortum, & Flynn, 2016, p. 30).

Interactive projects can amplify individual voices from groups that are frequently homogenized and stereotyped. For example, Daniel's interactive project, Blood Sugar (2010), features testimonies of 20 women who actively or formerly used drugs and are incarcerated in California prisons. The purpose of the project is to bring the women's narratives and "invisible" memories into the public realm. In a similar vein, The Quipu Project (Lerner & Court, 2015) an "interactive documentary/participatory oral history" project (MIT Open Documentary Lab, n.d.a), used local telephone networks in order to enable indigenous women in Peru to record testimonies about their experiences with forcible sterilization imposed by the regime led by Alberto Fujimori in the 1990s. With both of these projects, interactivity allows people across the globe to listen to the participants' audio testimonies. In communicating people's experiences, they help shape public memory about individuals and populations that have been marginalized and misrepresented. In spite of the potential of these initiatives, one of the most significant obstacles to shaping public memory through the construction of interactive projects is that over half the globe's population does not yet have access to the internet (Taylor, 2016). The digital divide between the developed and developing countries remains a significant issue. Even within wealthier countries, many people do not have online access.

## **Problematizing empathy**

There is a wide body of literature focused on affect and emotion as they relate to interactive technology and documentary, and I am interested in exploring this field in greater depth in future research. For the moment, however, I want to briefly highlight that with this project, my intention was to invite wider publics to feel empathy for Michael and others who face mental health challenges and may turn to drugs as a means of coping with various forms of pain. In this section, I problematize my attempts to generate empathy by pointing to scholars who have examined the role of this emotion in testimony research and journalism, and by reflecting on my personal experience with empathy while watching and commenting on a documentary about Palestinian people's human rights.

Megan Boler cautions educators and researchers about engaging in what she calls "passive empathy" (1997, p. 253). Unlike genuine empathy, passive empathy emphasizes what

separates interviewers and respondents, including status, and other inequalities. She explains that passive empathy cannot lead to social change or shifts in the conditions that oppress people and that it can perpetuate a sense of consumerism and voyeurism of others' suffering (1997, p. 254). Boler insists that in order for people to be truly empathetic with respondents, they must practice what she calls "testimonial reading" (1997, p. 257). This technique calls on researchers and individuals who learn about people's challenging experiences to consider their own involvement in the marginalization of others and to take appropriate action to help address these injustices (Boler, p. 261).

In reflecting on Boler's argument, I recalled my experience a few years ago after watching the documentary *Five Broken Cameras*, which I discuss later in this chapter. I remember feeling moved by the film, both as a filmmaker and a viewer, and I sent a short textbased message to co-director Emad Burnat on Facebook to share my thoughts. He promptly replied: "It's not enough to like the film" (personal communication, date unknown). I recall feeling challenged by his response and unsure of how or if I should reply. Reading Boler, I see that Burnat's comments were appropriate and deliberately provocative. It was insufficient for me to praise the documentary and his work and move on. Although I felt that I was empathizing with Burnat, his family, and Palestinian people whose suffering is highlighted in the documentary, I was experiencing and expressing passive empathy. I watched the film, was emotionally affected for a brief period, and although it helped, in part, to inform me about the oppression of the Palestinian people, their suffering did not remain at the forefront of my consciousness for long.

After reading Burnat's message to me, I began to feel powerless and unconvinced that I could do anything that would make even a small difference. Boler describes responses like this as a form of "self-protection" (1997, p. 254), which many others experience while learning through the media about suffering and injustices that take place on a daily basis. Susan Moeller coined the term "compassion fatigue" to refer to how people often feel "overstimulated and bored all at once" (1999, p. 3) in the face of endless media stories about human suffering around the globe. She suggests that people often numb out and "turn the page," but emphasizes "in turning away we become culpable" (1999, p. 2). Boler argues that apathy leads people to become detached from each other and blocks us from taking meaningful steps (1997, p. 254). Vietnamese Buddhist monk, teacher, and activist, Thich Nhat Hanh offers the following instruction: "Mindfulness must be engaged. Once there is seeing, there must be acting. Otherwise, what's the use of seeing?" (1992, p. 91). Fomenting social change must begin with people listening and

developing *genuine* empathy (Felman and Laub, 1992, p. 68). This requires interviewers to acknowledge their complicity in others' suffering in order to transform their own thinking in self-reflexive ways (Boler 1997, p. 255, 263).

Lisa Taylor, Umwalli Sollange, and Marie-Jolie Rwigema argue that empathy, which they describe as "feeling bad about feeling good about feeling bad" (2015, p. 106), may on the surface seem productive. Yet, they also claim that it is not effective in supporting genuine social change. Rather than focusing on generating empathy, they explain it can be more helpful for educators and scholars to invite publics to question what they have not learned about instances of injustice, oppression, and mass violence. They add that citizens must also ask what the gaps in their knowledge have shielded them from and what else they may not be aware of. In summary, they allege that the "rush to empathy [can be] a form of not-knowing" (2015, p. 106). The authors make an argument similar to Boler's, and build upon Sharon Todd (2015), who highlights the need for people to interrogate their own responsibility "in relation to another's suffering" (2015, p. 107).

Lilie Chouliaraki and Tijana Stolic explore empathy in the context of the ongoing Syrian refugee crisis. They argue that while reporting on the situation, journalism organizations in Europe managed to generate empathy among publics toward civilians fleeing the violence in their home country. At the same time, they claim that media organizations stirred up feelings of "suspicion or hostility" toward immigrants, largely after the November 2015 terrorist attacks in Paris (2017, p. 1163). Chouliaraki and Stolic insist that media images of refugees fail to fully humanize these individuals. They argue that it is vital that journalism organizations go further and strive to encourage publics to examine what Hans Jonas (1984) refers to as 'substantial' responsibility and Roger Silverstone describes as the "responsibility for the condition of the other" (2006, p. 152). In order to do more fully humanize refugees, Chouliaraki and Stolic claim that media organizations must attempt to provide individuals with opportunities to communicate their own experiences and goals (2017, p. 1164).

Julie Salverson recalls a student play about Bosnian children whose lives were impacted by land mines. She describes the performance as "a tableaux [sic] of disaster, which segued into first person narratives declaring stories of loss and dismemberment with heroics" (2001, p. 154). Although Salverson commends the students for the "sensitivity" and "skills" that they brought to the work, she argues that the play amounted to an act of voyeurism of tragedy and grief for the actors and audience. In her view, this occurred because the students "were not seeing themselves in the picture; and consequently, that we as audience members were neither asked nor able to implicate themselves" (2001, p. 154). The result, Salverson explains, is "audience and actors together were looking out at some exoticized and deliberately tragic other" (2001, p. 154-155). Although many people who watched the play indicated that they had felt moved by the performance, she insists it is more important to consider what the actors and audience members "obligations" are to those whose lives are depicted in the play (2001, p. 155).

I will continue to reflect on what I could potentially do in order to encourage people who engage with the digital memorial to consider their own responsibility in Michael's fatal overdose and those of thousands of other individuals. Like some social documentary makers, I could incorporate a "take action" element in the online project. For example, I could invite people to contact policy makers in their communities in order to encourage them to implement more early intervention programs for people with mental health challenges. I also could encourage citizens to purchase Narcan and carry it with them in order to potentially reverse drug-related overdoses. One thing I will certainly do is continue to lead research projects aimed at assisting marginalized people who use drugs, individuals who are in recovery from substance use disorder, and others who are affected by the opioid crisis, in order to assist them in communicating their personal experiences, aspirations, and humanity.

# **Examples of counter-memorials**

In this section, I highlight a number of counter-memorials that have been produced in response to a range of critical issues, including the bombing of an Air India passenger jet in 1985, violence against women, murdered and missing women in Canada, the Holocaust, and historical and ongoing rights violations committed against Palestinians. I outline how these counter-memorials' creators have used a variety of media, including physical objects, creative writing, oral history, testimony, photography, and documentary video to disrupt official silences and challenge dominant media narratives. I begin by exploring a small number of physical and digital counter-memorials for people who have died as a result of drug-related overdoses that have been developed in Australia, Canada, and the US.

## Physical counter-memorials for people who have died from opioid overdoses

In April 2017, a memorial for individuals who have died from opioid overdoses in Vancouver's DTES was erected on a lot owned by the city at 62 East Hastings Street. Brother Jopa, a musician who goes by the name Vertesi, collaborated with the Vancouver Mural Festival to create it. It consists of a wall where people can write messages about individuals who have died in drug-related incidents. According to local harm reduction advocate Sarah Blyth, the memorial is often the first place where people in the neighbourhood learn about who has passed away (Lupick, 2017b).

There have been other informal and temporary counter-memorials for individuals who have died from opioid overdoses in the DTES. For example, in September 2017, dozens of people in the community painted more than 2,000 wooden posts with the names of individuals who have experienced fatal overdoses in B.C. since 2014 (Lovgreen, 2017). The posts were placed in Oppenheimer Park in the neighbourhood. Later they were sent with messages that people wrote by hand in a coffin to Ottawa where they were showcased in Parliament. The goal was to pressure authorities to ensure that people have access to safe drugs, including heroin and methadone, instead of consuming street drugs that are often contaminated with fentanyl and carfentanil. The temporary memorial was created 20 years after activists in the community placed 1,000 crosses in the same park in order to call on decision makers to create harm reduction programs for individuals who use drugs as well as health care programs for people with HIV.

In 2001, Sue-Anne Ware (2008) produced what she called an *Anti-Memorial to Heroin Overdose* in Melbourne, Australia. That year, 331 people died from drug-related overdoses in the city (Melbourne Festival, 2001, p. 50). Ware's counter-memorial was constructed using planter boxes and the personal effects of people who have died from opioid overdoses were displayed in resin plaques. Tributes for the deceased were stenciled in pedestrian areas. In contrast to official memorials that often feature sculptures and become known as places of reverence, this countermemorial was informal and highlighted the experiences of marginalized individuals who are part of a population that is commonly overlooked by the state. Peta Malins argues that when people who use drugs die from overdoses, there are rarely ever public and compassionate displays of grief for them. When drug-related deaths are reported in the media, she writes that those who have died are often represented in reductive ways as "victim[s]," "addict[s]," or "recovering addict[s]" (2004, p. 491).

Ware's counter-memorial functioned differently and allowed people to openly mourn and honour decedents who were represented as unique individuals. The project was designed to shape public discourse and challenge commonly held views that people who use drugs are

"junkies" and "human refuse" (Ware, 2008, p. 66). It was also intended to counter government campaigns in Australia that portrayed people who use drugs as "diseased, psychotic, unpredictable and irrational" (Malins, 2009, p. 3). Ware's goal was equally to pressure authorities to make needle exchange programs more readily available in spite of considerable public opposition expressed by community groups, media organizations, and decision makers about this (Malins, 2009, p. 5). Unlike conventional memorials that are mostly meant to be permanent, Ware's counter-memorial was displayed for a short period of time at an arts festival. She stresses that she was building upon Young's vision of counter-memorials and his argument that they are meant to "provoke" instead of "console" (1993, p. 30). She deliberately constructed the memorial to be impermanent so that it would not be viewed as sacrosanct, and invited people to violate it, and actively take part in memorializing. By ensuring that it would not become a permanent construct, she was attempting to reflect the way the past and people's thinking about it constantly evolves. Ware (2004) argues that it is important to regularly consider, investigate, and confront questions related to substance use, fatal overdoses, and how they are remembered (p. 492).

Similarly, in 2016, Harm Reduction Victoria in Australia created temporary public memorials in order to draw attention to the rising number of opioid-related deaths and resist problematic messages about people who use drugs. A group of Melbourne artists were contracted to create murals, and they displayed the words "Overdose Awareness Day" along with the names of individuals who died from overdoses in an alleyway.



Fig. 1. Harm Reduction Victoria (Australia). "Rest in Paradise." (2016).

The purpose of these counter-memorials for individuals who have died from opioid overdoses was to communicate to people who passed by on foot that decedents were worthy of being mourned, to challenge ways that individuals who use drugs are predominantly portrayed as social outcasts, and to call on governments to do more to prevent further overdose deaths. These are meaningful counter-memorials in light of the widespread stigmatization of people who use drugs in official health campaigns and the Australian government's failure to provide sufficient harm reduction services. The initiatives helped raise awareness about the rising number of drugrelated overdoses in Australia, but according to Malins, they likely did not lead authorities to take action. She states that counter-memorials such as Ware's can help "generate more empathy" among the public and decision makers who "engage with it." However, she adds that local authorities in St. Kilda, the suburb where Ware's memorial was located, and Port Philip, the local government municipality that it is situated in, have not yet provided a safe injection site (SIS) in the area. This is something that harm reduction advocates have been calling for. Although one SIS exists in Melbourne, it was only opened in 2018. According to Malins, there have been no other "improvements or decreases" (personal communication, Oct. 30, 2018) in harm reduction since Ware's memorial was built.

Meanwhile, the opioid overdose crisis in Australia has intensified in recent years. According to the Penington Institute (2017), 2,203 people died from illicit drug overdoses in Australia in 2015. The number marks a significant increase from 2001 when 1,313 fatal overdoses were reported in the country. Malins (2016) argues that the country's education and public health systems continue to disseminate stigmatizing messages about people who use drugs. She claims that these troubling narratives have contributed to a lack of empathy among the public toward vulnerable individuals who use drugs. Malins suggests that this means fewer people may be inclined to seek medical care and may make riskier choices associated with drug use that could heighten their chances of overdosing.

## Digital counter-memorials for people who have died from opioid overdoses

In spite of the historic reluctance of people to publicly reveal that their loved ones died from drug-related overdoses, some individuals are starting to share this information in obituaries for their loved ones (Seelye, 2015). Others are choosing to disclose this information in newspapers and on obituary-specific websites such as legacy.com, obitsforlife.com, and dailyitem.com (Armstrong, 2016). Some individuals who have died from drug-related overdoses are being commemorated through a small number of digital memorials. *Celebrating Lost Loved Ones* (Lindemann, n.d.) allows anyone to post images, text-based memories, and tributes to deceased people, as well as indicate where they lived on an interactive map. The project was created by Colorado-based software developer Jeremiah Lindemann, whose 23-year-old brother James, or J.T., died from an oxycodone overdose (Singh, 2018). The project has since been moved under the purview of the National Safety Council < https://memorial.nsc.org/index.html>. As of June 22, 2018, there were 1,503 entries on the website. Many posts communicate authentic grief and reveal details of who decedents were and how they touched others' lives. Many indicate that the individuals who died first became addicted to drugs after being prescribed pain medication. Several also call for more harm reduction programs. Considered on their own and collectively, these memorials humanize people who have died and reflect the significant grief that their loved ones have experienced following their deaths. *Celebrating Lost Loved Ones* (Lindemann, n.d.) has the potential to grow, as the number of overdose deaths continues to climb and because there are no restrictions on who can contribute to the project other than the fact that people need access to computers and the internet.

A less technologically sophisticated virtual memorial was created by Brandon Costerison (n.d.) in response to opioid overdose deaths in the St. Louis, Missouri area. People who are interested in contributing photos and text-based eulogies are invited to contact Costerison directly. As of December 2018, there were tributes to 19 individuals on the website. Many of the commemorations that appear on the site are written by family members and friends of those who passed away, and several feature lengthy descriptions of genuine pain and loss. These messages highlight the significant impacts of the deaths for people who were intimately and closely connected to individuals who died.

These two digital memorials for people who have died from opioid overdoses disrupt ways that journalists and photographers predominantly represent people who use drugs and individuals who have died from opioid overdoses, and contribute to the silencing of survivors. The producers of these innovative memorials and those who have contributed to them have created their own systems and methods in order to "overcome" dominant and oppressive "rules" (Foucault, 1977, p. 86). Every person who experiences a fatal overdose is worthy of being commemorated, and these digital memorials have created opportunities for people to do so. The narratives that have been shared on these websites help to resist dominant narratives about the opioid crisis. They are, however, limited, in terms of the number of people who are remembered

and the depth of sharing from people who have contributed to them. By engaging in sustained and collaborative testimony production with bereaved people, as I did in this project, I believe it is possible to document even more nuanced perspectives.

## The Air India disaster

At first glance, connections between the Air India disaster and the opioid overdose crisis may not be apparent. However, examining how the Air India tragedy was officially remembered, in contrast to how a group of scholars and artists have produced counter-narratives about the event, reveals how counter-memorialization tactics are relevant in the context of the opioid crisis.

The bombing of Air India Flight 182 on June 23, 1985 en route from Montreal to Delhi was the worst mass-attack in Canadian history. In spite of the fact that 329 people, including 280 Canadian citizens were killed, the federal government and the public have largely viewed it as an Indian tragedy, thus overwhelmingly failing to view it as a Canadian issue. In the wake of the disaster, for example, then-Prime Minister Brian Mulroney conveyed his sympathies by phone to Indian Prime Minister Rajiv Gandhi. This was a clear indication that Mulroney considered it a foreign issue. That the attack was orchestrated and coordinated by Sikh extremists in B.C. and that so many Canadians perished did not seem to matter to Mulroney. The families of those who died aboard Flight 182 have not been adequately recognized by decision makers and the citizens of this country and they have largely had to grieve in silence. Former Prime Minister Stephen Harper publicly apologized for the government's failure to prevent the attack and for its neglect of decedents' families (Reinhart, 2018). He also launched a commission of inquiry into the disaster that framed the event as one that was plotted in Canada, carried out by Canadians, and primarily affected Canadians. However, according to Chandrima Chakraborty, Amber Dean, and Angela Failler, these initiatives were designed to bolster the government's anti-terrorism policies (2017, p. xi). They argue that officials did nothing to address the prejudices that contributed to years of government neglect of the decedents' families. Many people in Canada remain underinformed about the Air India disaster and do not think it is something that happened to citizens of this country. There have been few scholarly explorations about the attack that focus on issues other than the roots of terrorism in Canada and how further incidents can be prevented. Remembering Air India: The Art of Public Mourning, edited by Chandrima Chakraborty, Amber Dean, and Angela Failler (2017), highlights a number of scholarly, creative, and artistic projects

that aim to shatter the silences imposed on the loved ones of those who perished in the disaster, encourage the public to witness and acknowledge their suffering, and generate new public memories about the incident (2007, p. 288).

Many of the works of fiction, poetry, film, and dance that are published or examined in the book were produced by individuals who are related to people who died on the Air India flight. Many of the contributors draw linkages between the mishandling of the disaster by the Canadian government and its failure to support the families of those who were killed to historical incidents in India and Canada. For example, novelist Padma Viswanathan draws parallels between the airline bombing and past instances of racism and sectarian clashes. These include anti-Sikh violence that occurred in Delhi and surrounding areas in 1984 in which more than 3,000 people murdered, the Indian military's attack on the Golden Temple in Amritsar, and the Canadian government's refusal to allow the *Komagata Maru*, a steamship carrying 376 migrants, to dock in Vancouver. The decision to turn the vessel away was a reflection of the government's efforts to stem immigration of non-white populations. This layered historical exploration of the Air India bombing disrupts official narratives that the disaster was a foreign tragedy (Viswanathan, 2014, p. 13-14). Anita Rau Badami also challenges dominant narratives about the Air India attack in her novel Can You Hear the Nightbird Call? (2006, p. 15-17). She also connects the tragedy to the Komagata Maru and Canada's racist immigration policies and suggests they contributed to the rise of militant Sikhism (2006, p. 18).

According to Failler, during the official inquiry into the Canadian government's response to the bombing, there were deliberate attempts to discredit efforts by artists and writers to make sense of the tragedy. This silencing of diverse points of view was intended to strengthen the inquiry's assertions that its own interpretations of what had transpired were the only legitimate narratives (Failler, 2010, p. 117). Failler adds that by opposing attempts to dismiss alternative understandings of the bombing and its aftermath, creative producers are able to challenge the legitimacy of the state and its rhetoric. The artistic and creative projects that are examined and published in *Remembering Air India* (Chakraborty, Dean, & Failler, 2017) communicate nuanced and complicated stories about the roots of the bombing, how the Canadian government responded in inadequate and shameful ways, and the lasting impacts of the tragedy for the loved ones of those who died in the disaster. These projects and the book itself have helped create new and important counter-memories about the disaster and official responses to it.

#### Violence against women, and murdered and missing women

Examining a number of counter-memorials that have been created in order to acknowledge women who have experienced violence, as well as women who have been murdered or gone missing, also affirmed my sense that creating a counter-memorial about Michael was appropriate and that it could help resist dominant narratives about the opioid crisis. Counter-memorials focused on violence and murdered and missing women trouble narratives that obscure the nature and minimize the scale of the problem (Bold, Knowles and Leach, 2002, p. 126). They also serve as a call for government action. In spite of the affordances of these initiatives, their producers have often faced significant resistance. Local governments have insisted that the memorials be placed in areas that are not very visible and have given their designers little funding (Bold, Castaldi, Knowles, McConnell, & Schincariol, 2007, p. 6-7). Nevertheless, the creators have persisted and today there are number of physical memorials in Canada that commemorate women who have been murdered by men, including the 14 female students who were killed at l'Ecole Polytechnique in Montreal on December 6, 1989. In Montreal, a memorial wall was built to honour the women.

In Vancouver, The Women's Monument Project created the *Marker of Change* to commemorate all women and girls who have been murdered in Canada. This monument, which was constructed in Thornton Park in the DTES, consists of 14 granite benches and the names of the women who were killed in the Montreal Massacre are engraved on them. Toronto artist Beth Alber designed the memorial and explains that the way the benches form a circle is meant to facilitate healing and represents "a protected or consecrated space" (Alber, n.d.). Dean argues the memorial does not sufficiently communicate the fact that dozens of women have been murdered and disappeared from the neighbourhood where the memorial is situated (2015, p. 125-126). She claims that it helps perpetuate the notion that some women, including those who were killed in the Montreal Massacre, are more grievable than others. Many of the women who were killed or went missing from the DTES were Indigenous.

According to Brenda Longfellow and Julianne Pidduck, temporary and long-term memorials that commemorate the Montreal Massacre have helped to increase awareness about violence against women. They insist that these memorials have contributed to a shift in the way policy makers in Canada and Quebec have communicated about the issue. They claim that the monuments have even influenced policies to protect women (2013, p. 5). Pidduck also argues that certain feminist audio-visual documentaries produced about the Montreal massacre

contributed to counter-memorialization about the tragedy (2003, p. 24). Some of the deceased women's families as well as students who attended the Polytechnique claimed feminists were capitalizing on the attack to further their own agendas. However, some individuals who were closely and intimately connected to the decedents offered testimonies that were featured in documentaries. These narratives helped disrupt political discourse that denied the fact that the women's murders were a reflection of systemic violence against women. Some of the arguments articulated in documentaries also challenged mainstream media organizations' views. For example, Maureen Bradley recounts how Barbara Frum, co-host of *The Journal* on *CBC Television*, refuted the possibility that the shootings were linked to hatred against women (2006, p. 931). Bradley recalls that mainstream news organizations even hesitated to refer to the killings as a massacre, which it clearly was (2006, p. 934).<sup>15</sup>

Another Canadian tragedy linked to systemic misogyny is the murder and disappearance of dozens of women connected to Vancouver's DTES. Police have identified 69 women from the neighbourhood who have been killed or are missing (Demi, 2018). After the bodies of women who disappeared from the DTES began to be identified at the Port Coquitlam, B.C. pig farm belonging to Robert Pickton, families of those who were killed set up informal and temporary memorials involving candles and photographs at the site. Pickton was ultimately charged with six counts of second-degree murder, and the remains or DNA of 33 women were found on his property (Gollom, 2018). In response, a memorial boulder in CRAB Park near the Port of Vancouver in the DTES has been engraved with the words "THE HEART HAS ITS OWN MEMORY." Every year, ceremonies are held at the stone and a nearby bench to honour the missing and murdered women from the community.

There have been attempts to build permanent memorials at site of the former Pickton farm. However, some of the decedents' families have opposed the plans (Bold, Castaldi, Knowles, McConnell, & Schincariol, 2007, p. 7). Other physical memorials for murdered and missing women have been met with resistance. Organizers of an initiative known as *Living Stones* planned to lay 62 commemorative bronze plaques in the DTES in places where women who are missing or murdered were last seen (The Canadian Press, 2015). Although some of the women's family members were reportedly in favour of the project, others opposed it. The City of Vancouver cancelled the initiative in 2013 after it came to light that one its principle designers

<sup>&</sup>lt;sup>15</sup> In 1995, Bradley released a documentary titled *Reframing the Montreal Massacre: A Media Interrogation* in order to further articulate her perspective.

had been involved with a series of crimes. At the time the project was terminated, only four plaques had been installed.

Dean writes that the most effective counter-memorials invite people to remember in strategic ways and "as a difficult return" (2015, p. 120). Drawing on Roger Simon, Sharon Rosenberg, and Claudia Eppert (2000, p. 3-4), Dean argues that it is beneficial for people to reflect on how injustices affect present-day circumstances and not only dwell on them as historical events. She also urges ordinary citizens to reflect on their own potential involvement in the events and issues they are commemorating. According to Dean, the stone and bench at CRAB Park encourage visitors to engage in strategic remembering. She claims that the memorial has helped create awareness about the fact that the women had gone missing from the neighbourhood and that it has become a primary place for people from the DTES to commemorate those who disappeared or were killed (2015, p. 123). However, Dean argues it fails to communicate the broader social conditions that continue to exist that contributed to the women's murders and disappearances. The situation has not been resolved, even though a serial killer is behind bars (2015, p. 124).

One of the temporary memorials that was created to commemorate women who have been murdered or gone missing from the DTES was a video-art installation by Janis Cole and Rebecca Balmore (Dean, 2015, p. 127). Known as *Remember their Names*, the project was showcased in Toronto's Trinity Square for four days in August 2009. It used personal objects that belonged to the women, including stuffed animals and written cards, as well as photographs of them, many taken when they were children. These objects were donated by decedents' families and highlighted the women's personal and family connections (Dean, 2015, p. 129). Unlike many other memorials for women who have been killed and disappeared from the DTES, the art-installation used the women's names in order to invite visitors to remember the women as individuals as opposed to a cluster of people whose unique identities have often been glossed over (Dean, 2015, p. 129).

These memorials for murdered and missing were produced differently than the digital memorial that my collaborators and I constructed for Michael. However, their creators' attempts to disrupt official silences about systemic violence against women and its connection to misogyny were instructive and inspiring to me as I conceptualized and produced the project.

## **The Holocaust**

The events of the Holocaust have led a number of artists to create counter-memorials that are specifically designed to disrupt dominant narratives communicated by the German state. Examining the philosophical orientations and designs of some of these projects enabled me to understand the value of producing a counter-memorial in the context of the opioid crisis.

Between 1949 and the 1970s, the government in Germany constructed numerous physical memorials to remember the Holocaust. These include plaques and signs that identify where Jewish communities lived, prayed, and buried their dead before the war (Harris, 2010, p. 34). The German state also erected official monuments at the sites of death camps where Jews were imprisoned and murdered (Harris, 2010, p. 35). According to Young, critics believe that many official monuments lead people to not want to engage with the past (1999, para. 12). Since the mid-1980s, a number of artists in Germany have constructed a number of innovative, abstract, and thought-provoking counter-monuments in order to recall the Nazi genocide. Cecily Harris claims that these counter-memorials delivered "anti-authoritarian" messages, but also grappled with the challenge of "representing the un-representable" (2010, p. 35). She argues that many of these initiatives attempted to engage people in active remembering (2010, p. 43) as a means of challenging the widespread sense of indifference that many German citizens feel about the Holocaust (2010, p. 36).

These counter-memorials reflect many scholars' criticisms about state-sanctioned commemorative monuments. For instance, in the 1800s, Friedrich Nietzsche called for an end to the construction of German memorials, claiming they led to restricted memory-making (2006, p. 14-17). Lewis Mumford argued in the 1930s that stone monuments meant to symbolize immutability were largely built by states concerned with communicating their own power (1938, p. 438). According to Young, Germans continue to view monuments with a considerable level of apprehension, because the Nazis used them as symbols of their domination over much of Europe while engaging in widespread destruction and mass murder (1999, para. 11). Martin Broszat insists that rather than remembering historical events, monuments often conceal the truths of these incidents beneath layers of national propaganda (1990, p. 129). According to Rosalind Krauss, monuments built in the modern era are often ineffective in supporting memory-making about historical events, because they often point back to themselves instead of generating wider discussions (1988, p. 280). Pierra Nora (1989) argues that monuments often limit the ability of groups to produce their own embodied and personal memories.

In 1987, artist Horst Hoheisel designed a counter-monument to recall how Nazis had dismantled a fountain in 1939 that had been built in the main square of the city Kassel in 1908 (1999, para 14). Funds for the original project had been provided by Sigmund Aschrott, a Jewish businessman. As a result, the Third Reich viewed it as a symbol of Jewish influence on German society. In the 1960s, German organizations began to advocate for the reconstruction of the fountain. Hoheisel felt this could lead to the erasure of what had happened to the structure from public memory. He came up with a "negative-form" design and built a replica of the original fountain and inserted it upside down twelve meters below ground. The work is visible through glass panels, and people who visit the counter-memorial are encouraged to actively take part in the commemorative process by peering into the ground. Hoheisel argues that the underground fountain serves a different function than most official memorials in that it invites people "to search for the memorial in their own heads (translated by Young, 1993, p. 46).

In 1995, Germany held a national competition and sought submissions from the public for a Holocaust memorial. Instead of constructing another monument, Hoheisel proposed that the Brandenburg Gate in Berlin be destroyed and its remnants covered with stone pallets. Hoheisel recognized that his plans would never been approved, but he felt it would be an appropriate and illustrative way to symbolize the murder of six million Jews (Young, 1999, para. 14). In spite of Germany's attempts to build physical memorials about the Holocaust, Hoheisel claimed that "only an unfinished memorial process can guarantee the life of memory" (Young, 1999, para. 14). Hoheisel believed that permanent memorials risked sending a message that the Nazi genocide committed against Europe's Jews was resolved in the national psyche and memory. He preferred a vision of a counter-memorial that would keep the memory of the Holocaust alive in evocative ways.

A temporary counter-memorial built in Hamburg in 1986 called the *Monument against Fascism* was designed by Jochen Gerzes and Esther Shalev. It consisted of a massive metal tower constructed on the grounds of a strip mall. The location was significant, because in contrast to official monuments, it was not created in an area designated by the state. Ordinary people were invited to write their names on its lead surface, which allowed them to become active participants in the memorial process. Some individuals left notes professing their love for others, and some even inscribed it with Nazi symbols (Harris 2010, p. 45). By 1994, the column was deliberately buried beneath the earth's surface and had totally vanished from sight. According to Harris, the fact that the memorial was intentionally buried but continues to "exist underground" (2010, p. 46), symbolizes the mass murder of Jews and their near-total eradication from Germany. Andrew Causey explains: "Against the permanence of the monument, the counter-monument is about absence, disappearance, and trace" (1945, p. 2018). Gersez and Shalev aimed to do what most official state monuments fail to accomplish, namely to engage people in actively questioning and searching for meaning about their own connections to the historical events that they allegedly recall. Young adds that "public memory and its meanings depend not just on forms and figures in these memorials, but on the viewer's responses to them" (1993, p. xii).

In 1990, Christian Boltanski created a counter-memorial known as *Die Endlichkeit der Freiheit*, or *Missing House*, as the title is translated in English, using photographs, drawings that children had made, writings, and other materials (Young, 1999, para. 29). His aim was to symbolize how Jewish Germans in Berlin had been forced from their homes, and non-Germans had been allowed to move into them. Artist Micha Ullman built a counter-memorial to encourage people to remember how the Third Reich held book burnings on May 10, 1933 in many German cities (Young, 1999, para. 31). Ullman's memorial comprises empty book shelves set in the ground beneath plate glass on a cobblestone street in Berlin. A plaque is engraved with Heinrich Heine's words: "Where books are burned, so one day will people be burned as well" (qtd. in Young, 1999, para 31). Austria's most prominent memorial for 65,000 Jewish people who died in the country during the Holocaust was designed by Rachel Whiteread, a sculptor from England, and is referred to as the *Nameless Library* (Young, 1999, para. 31). It is a counter-memorial, because unlike official monuments that tend to feature literal designs, it uses empty space to symbolize books on library shelves that cannot be read.

## Palestine

## Sama Alshaibi's memory work

The creation of the state of Israel led to the forcible exodus of 800,000 to 900,000 Palestinians who resided in the area (Said, 2012). Artist Sama Alshaibi has explored the personal histories of members of her own family who were forced to abandon their homes in historical Palestine and seek refuge in Iraq before moving to the U.S., back to the Middle East, and ultimately returning to live in America (2006, p. 37). She writes that she attempted to resurrect the memories of her loved ones and others whose lives were directly affected by the historical event that Palestinians refer to as the Nakba, or the catastrophe, as it is translated in English. She explains that many of her relatives' memories were frozen by years of displacement from their ancestral homeland (2006, p. 39). In recounting them, Alshaibi explains that she is helping to tell the narratives about the pasts of all Palestinians and about life in exile and under Israeli occupation (2006, p. 37). She adds that these stories are little known in the West, because very few memorials have been created about these events (2006, p. 39).

In interviewing various family members and writing a memoir and producing creative photographs based on their experiences, her work resists dominant memory and "official history" (Alshaibi, 2006, p. 31). She claims that she challenges Israeli mythology that suggests its citizens have experienced the lion's share of suffering in their ongoing conflict with the Palestinians. She insists that Israel's narratives have become the most widely recognized and have contributed to the silencing of Palestinians' voices and memory. Alshaibi adds that that her work counters Israel's insistence that the violent actions it has conducted against its enemies, including Palestinians, have been in the interest of security. She also challenges Israel's contention that Arab states advised Palestinians to go into exile, which made it possible for Jews entering the country to settle in their homes and land (2006, p. 31). Alshaibi insists that she is interested in "reclaiming a history" and expressing herself in order to shatter silences imposed by Israel as it tyrannized and subjugated Palestinians while "demonizing" (2006, p. 31) their national identity.

In order to generate counter-narratives, Alshaibi photographed herself as well objects that hold special meaning to her, including a traditional headdress, anti-occupation graffiti, illustrations, as well as text-based messages drawn on her body. Her memory-making about women in her family, including her grandmother, as well as people she is not related to, can be viewed as counter-narratives, because Palestinian women's personal stories about the Nakba have been largely dismissed as a result of colonialism, occupation, gender relations, and Palestinian nationalism. Alshaibi took photographs and produced video images of her return to places in the Occupied Territories and Israel where her grandparents were forced to flee from. By documenting elements of her grandmother's experiences, Alshaibi ruptures silences and imposes her family's private memories on cultural memory. She creates counter-narratives that many other Palestinians can relate to (2006, p. 41). Her work is also effective because she is confronting challenges that her family members are still experiencing (2006, p. 41). Although she did not personally experience the same difficulties as her parents, grandparents, and other

family members, her life was nonetheless shaped by them (2006, p. 42). Marianne Hirsch describes this phenomenon as "postmemory."<sup>16</sup>

## **Breaking the Silence**

Breaking the Silence (BTS) is an organization founded by former Israeli soldiers who are committed to speaking out and informing others about rights abuses committed by Israeli security forces against Palestinian people. In May 2004, BTS began gathering and disseminating testimonies of soldiers who have served in the Israeli military. Many of the initial narratives focused on what soldiers witnessed in Hebron during the Second Intifada, which began in September 2000 and reached its climax two years later (Katriel & Shavit, 2011, p. 77). BTS showcased photographs that former soldiers had produced while on active duty in the West Bank and initially did not intend to share publicly. The exhibition was held outside Tel Aviv. In addition to these images, it included video-recorded testimonies from ex-soldiers. The veterans' words helped give the photos meaning, and the fact that they spoke about actions they took part in and witnessed made their testimonies credible, enlightening, and convincing (Katriel, 2011, p. 114). For those who participated in the exhibition, offering their testimonies was an act of defiance, an attempt to inform wider Israeli society about the situation, and a plea to authorities to change the way they operate in the occupied territories (Katriel, 2011, p. 115).

BTS has adopted innovative methods of publicly sharing soldiers' private memories and testimonies and helping people hear from Palestinian people in order to influence collective memory. It staged the exhibition in the Knesset, Israel's parliament, and has developed ways of sharing recently recorded testimonies on the organization's website and social media channels (Katriel, 2011, p. 116). Representatives of the organization regularly take part in public forums and bring visitors to Hebron, where veterans provide them with information about the impact of Israeli occupation (Katriel, 2011, p. 116).

Veterans' testimonies are powerful counter-narratives that are helping to educate wider Israeli society about its moral culpability in the crimes that have been committed against Palestinians (Katriel & Shavit, 2011, p. 79). By sharing personal memories, former soldiers are bolstering growing criticism about Israel's conduct (Katriel & Shavit, 2011, p. 78) and

<sup>&</sup>lt;sup>16</sup> Marianne Hirsch (2001) defines postmemory as the connection that children have to the experiences of their parents who survived cultural or collective trauma. These experiences are ones they solely recall as narratives and images that they were raised with, but are so potent and significant that they create memories in their own right.

disseminating knowledge about the situation that could potentially lead to a disruption in the status quo (Katriel & Shavit, 2011, p. 80). Many military and Israeli government officials, media organizations, and celebrities have repeatedly denounced BTS and its controversial messages as unpatriotic and treasonous (Katriel, 2011, p. 117-119). In spite of these public attacks, the organization believes that change must start by opening people's eyes to the reality on the ground in the occupied territories.

The Israeli government and major journalism organizations do not communicate this kind of information (Katriel & Shavit, 2011, p. 86).<sup>17</sup> Israeli officials have begun preventing activists who document rights violations committed by its security forces against Palestinians and individuals who support the Boycott, Divest and Sanctions (BDS) movement, an international effort to pressure Israel to respect Palestinians' rights, from entering the country (Landau & Berger, 2018).

## **Documentaries about Palestinian rights**

Photographers and documentary makers have helped shape public memory about some of the most destructive conflicts of the 20<sup>th</sup> and 21<sup>st</sup> centuries. Many have been motivated by a desire to inform wider society about the impacts of war and effect change.<sup>18</sup> Their work illustrates the potential for counter-narratives to inform publics and in some cases mobilize citizens to advocate for governmental responses.

Roxana Waterson claims that independent filmmakers have a unique ability to disrupt "officially imposed silences" (2007, p. 51). She insists that film is able to influence memory, because it offers information about the past that is often performed, and this helps to communicate different types of knowledge that are received by viewers over lengthy periods of time. By exploring their personal experiences connected to historical events and systemic issues, Bill Nichols argues that documentary makers can create "credible, convincing, and compelling [narratives] without being definitive or conclusive" (2001, p. 51).

<sup>&</sup>lt;sup>17</sup> Reporters in Israel are required to present their stories and packages about the country's security and relations with other countries to the military's censor before they are published. This has been the law since Israel declared its independence and officials say it is intended to help protect the country. In 2017 the Israeli military reported that 21 percent of the journalism stories that it reviewed were completely or moderately edited (Matar, 2018).

<sup>&</sup>lt;sup>18</sup> For example, German photojournalist Anja Niedringhaus (www.anjaniedringhaus.com) documented the impacts of war through her work with Associated Press, and was killed by a police officer in Afghanistan's Khost province in 2014. James Foley (https://www.jamesfoleyfoundation.org/james-w-foley/) reported on people affected by conflict in northern Syria and was killed by ISIS militants in 2014.

A number of independent Palestinian documentary makers have produced countermemories about Palestinians' experiences resulting from the Nakba and ongoing injustices that they face at the hands of the Israeli military. The ways the filmmakers communicate their emotions and perceptions in these films allow viewers to witness the protagonists in the context of wider social and political conditions that affect them.<sup>19</sup> In spite of the gravity of the challenges that the filmmakers face and that they investigate and document, most demonstrate a capacity to not feel defeated, but to be courageous, and resilient (Katriel & Gutman 2015, p. 209). Many of these Palestinian documentary makers engage with filmmaking as a means of advocating for political change. Like many filmmakers who have been committed to documenting human rights issues, they also aim to shape collective memory.

One independent documentary produced in recent years is *Bil'in Habibti* (Carmeli-Pollak & Levin, 2006), or *Bil'in My Love*, as the title is translated in English, directed by Jewish-Israeli Shai Carmeli-Pollak. Another is *Five Broken Cameras* (Camdessus, Allegria Productions, Burnat Films Palestine, Guy DVD Films, 2011), co-directed and produced by Palestinian Emad Burnat and Israeli Guy Davidi. Both films focus on regular non-violent protests held by residents of the West Bank village of *Bil'in* in the first years of the 2000s against Israel's construction of a 202 km-long concrete separation barrier. Demonstrators in the village were infuriated because the wall threatened to cut them off from their land and lead to the destruction of olive trees that they depended on for their livelihoods.

In *Bil'in Habibti* (Carmeli-Pollak & Levin, 2006), the director chronicles his experiences and interactions as he takes part in the village's resistance efforts. He acknowledges that as a Jewish-Israeli activist and filmmaker, he is an outsider. In a dramatic scene in the film, a group of disabled people in wheelchairs begins staging a peaceful protest when Israeli soldiers start firing on them. As the soldiers approach the group, Carmeli-Pollak, who is not visible to the viewer because he is holding a video camera and filming, calls out and pleads with them to stop. "This is a demonstration of disabled people," he shouts. "There are disabled people here. Calm down! There are disabled people in wheelchairs. Don't shoot" (Carmeli-Pollak & Levin, 2006). His pleas are ignored, and the soldiers enter the village, and a commander is heard ordering the soldiers to occupy a local house. Dominant media organizations rarely broadcast this type of counter-narrative about the situation on the ground.

<sup>&</sup>lt;sup>19</sup> In his 2013 documentary, *Cinema Palestine*, Tim Schwab features interviews with the following Palestinian filmmakers and presents excerpts from their films: Mohammed Bakri, Sobhi al-Zobaidi, Nasri Hajjaj, Tawfiq Abu Wael, Annemarie Jacir, Emad Burnat, Najwar Najjar, George Khleifi, Mai Masri, Elia Suleiman, and others.

By filming incidents of Israeli military aggression in order to try to educate Jewish-Israelis and create change, Carmeli-Pollak adopts a tactic known as "mobilizing shame" (Keenan, 2004). The strategy has long been practiced by scholars and media producers who address human rights concerns and campaign for social and political justice (Keenan, 2004). It involves highlighting the actions of states, armed forces, and others in order to allow the public to assess their behaviour, inspire social discontent (Roth, 2004, p. 67), and mobilize public support for change (Avni, 2006). It is also a method of trying to compel powerful agents who violate internationally-recognized human rights norms to alter their behaviour (Keenan, 2004). Kenneth Roth writes that in order to effectively advocate for change, those who mobilize shame must do more than merely present disturbing audio-visual content (2004, p. 69). He argues that people must point to instances of oppression and also articulate ways of addressing the injustices that have been committed. If those who are guilty of committing violations are not directly highlighted, and if solutions are not put forward, people who have been affected by their wrongful actions can be weakened and affected even more negatively (Katriel & Gutman, 2015, p. 211). Visual media, including documentary, have the potential to communicate countermemories about individuals and groups who have been oppressed by presenting them as empowered, as they often are (Bishara, 2013). Both Bil'n Habibti (Carmeli-Pollak & Levin, 2006) and Five Broken Cameras (Camdessus, Allegria Productions, Burnat Films Palestine, Guy DVD Films, 2011), do this in compelling ways. Dominant media narratives frequently cast Palestinians as violent and menacing, or alternately as lacking in agency. Meanwhile, these two films present different and humanizing stories about Palestinian people at the frontlines of a military campaign that they have resisted for decades.

This alternative and realistic manner of representation can be seen in films made by Palestinians themselves. For years, Palestinian farmer Emad Burnat filmed Israeli military assaults on peaceful demonstrators in his West Bank community. In *Five Broken Cameras* (Camdessus, Allegria Productions, Burnat Films Palestine, Guy DVD Films, 2011), he tells the story of his growing family's life in these challenging circumstances. Burnat recalls moments when his video cameras are repeatedly shattered, including when one is struck by Israeli soldiers' gunfire. Although international journalists were often present in Bil'in during the demonstrations, Burnat's personal history and his role as an activist in the demonstrations while also chronicling the Israeli military's violent tactics on video, allow him to create unique counter-memories about the situation. Although Burnat recounts the events that took place in his village as a personal diary film, the documentary also reflects the experiences that his community lived through (Katriel & Gutman, 2015, p. 215).<sup>20</sup> In spite of the grave situation that Burnat, his family and his fellow villagers experience, the film presents them as courageous and empowered even as they seek change.

In a disturbing scene in the film, Burnat narrates: "Now that [my son] Gibreel is old enough to understand he comes to see the demonstrations" (Camdessus, Allegria Productions, Burnat Films Palestine, Guy DVD Films, 2011). As Burnat's voice conveys this information, the viewer sees Gibreel, who appears to be about four-years-old, propping himself up on the ledge of a white car with its front door open. The camera circles around the boy to reveal to the viewer what Gibreel sees. He watches as a group of Israeli soldiers arrests a male Palestinian protestor, who is clearly afraid and calls out, "What are you doing?" (Camdessus, Allegria Productions, Burnat Films Palestine, Guy DVD Films, 2011). There are sounds of bullets or tear gas canisters being fired. Gibreel tucks himself inside the vehicle as the camera records a number of Israeli soldiers passing close by on foot. The way the scene is filmed from a low vantage point with Gibreel's profile and darting eyes visible to the viewer and the soldiers just steps away heightens the sense of nervousness and intimidation that the boy must be feeling. As tear gas is fired and protestors are seen enveloped in a cloud of fumes, the viewer hears Gibreel coughing as Burnat tells him to roll up the car windows. Moments later, the film cuts to a scene in which Gibreel stands knee-high next to his mother, who is washing dishes in a sink in their home. The boy tells her: "Then the soldiers came and started shooting. They were everywhere. But I wasn't afraid. They were in front of Daddy's car." "And you weren't afraid?" his mother asks. "You weren't afraid they'd take you? Weren't you afraid, Gibreel?" As she speaks, his eyes widen and he softly responds: "Yes, I was." (Camdessus, Allegria Productions, Burnat Films Palestine, Guy DVD Films, 2011).

Examining these films was instructive for my project. I hope that the testimonies of my project's participants mobilize shame by pointing out that Michael's death and thousands of other fatal overdoses were preventable, and that governments must act to ensure that vulnerable people are protected. In the same way that Palestinians' voices have seldom been amplified by dominant journalism organizations in the West, the experiences of people who have lost loved ones to opioid overdoses have also been neglected and silenced. This project illustrates that my

<sup>&</sup>lt;sup>20</sup> The film's co-director and co-producer, Guy Davidi, acknowledges that although the film centres on Burnat and family, he also views it as a counter-narrative about the Palestinian people (*The Guardian*, 2012).

interlocutors and others like them who have been impacted by the opioid crisis have important and timely stories to tell, and that they deserved to be listened to.

## **Conclusion: Defending counter-memorials**

The examples that I examined in this chapter illustrate that there are benefits to humanizing deceased people's lives, whether they have died as a result of drug-related overdoses, violence, terrorism, or genocide. The purpose of humanizing Michael through this project is to communicate that it is possible to alter the discourse about the opioid crisis by working in collaborative and sustained ways with people who have been affected by it. There are, of course, other ways that Michael has succeeded in humanizing himself in manners that do not depend on emphasizing his connections with others, as I have done in this project. Since his passing, Carina has updated Michael's website, michaelstoneteaching.com. This has allowed her to offer the online courses that Michael developed and was preparing to release prior to his death. The evolving nature of his website also enables Michael to continue to have an impact. His books and archived podcasts also permit him to continue to make spiritual teachings available to audiences.

In this chapter, I examined scholarly sources on the case study approach and justified my decision to focus on Michael in an in-depth manner. I presented a rationale for framing and creating the project as a counter-memorial. Thereafter, I shared details of a number of counter-memorials that were created in response to the Air India disaster, violence against women, murdered and missing women, the Holocaust, and rights abuses in the Occupied Palestinian Territories.

In the following chapter, I present details about Greenspan's method of collaborative testimony research, other innovative approaches to recording survivor testimonies, and some of the limitations and ethical challenges of this work. I discuss how I adopted Greenspan's method and the process of recording testimonies with my collaborators. I also examine some of the breakthroughs and nuanced information that the participants communicated. The chapter ends with an overview of how I incorporated the narrative approach and continuing bonds theory in my interactions with my collaborators, how they crafted their grief and spoke to Michael in the present moment, and how they felt they changed as people in the process. I indicate how these methods allowed my collaborators to create testimonies that resist dominant media narratives about the opioid crisis and people who have experienced overdoses.

## **CHAPTER 3**

# **HOLOCAUST TESTIMONY**

## Introduction

My intention with this project was to assist my collaborators in recording their memories and testimonies about their connections to Michael as well as their grief experiences in ways that disrupt dominant narratives about the opioid crisis and individuals who have experienced fatal overdoses. I felt at the outset that traditional scholarly methods would not allow us to create new knowledge that would be beneficial to my collaborators and me. I first heard Henry Greenspan speak about his innovative approach to Holocaust testimony research at the Centre for Oral History and Digital Storytelling (COHDS) at Concordia University in 2015. As I explored his work in greater depth, I recognized that it would be appropriate to build upon his strategies in this project.

In this chapter, I provide further information about Greenspan's method and how he has implemented it. I highlight how his approach is different from how other influential organizations have produced testimonies with Holocaust survivors. I also discuss how other scholars have experimented with Greenspan's strategies and taken unconventional steps to create nuanced narratives with survivors that communicate knowledge that is not widely known. I also explore how my grandmother's wartime experiences contributed to my interest in Holocaust testimony research. I then discuss some of the risks and ethical implications of this work. Thereafter, I examine the controversial notion of trauma in Holocaust testimony. The chapter ends with a discussion of commodification, voyeurism, and cultural colonialism in testimony research, and some of the cultural expectations that Greenspan claims influenced his work with survivors.

# "Learning together" and "knowing with"

When Greenspan began interviewing Holocaust survivors over 40 years ago, he was interested in developing a method that he hoped would produce beneficial and nuanced knowledge and would avoid harming survivors. Greenspan was not the first person to interview witnesses, but there were few established ways of doing so at the time he began his work. Over the next decades, he engaged in long-term, sustained, and collaborative testimony production with a small number of survivors. Well-known organizations, including the Shoah Foundation at the University of Southern California, and the Fortunoff Video Archive at Yale University, have recorded one-time, video-recorded testimony interviews with tens of thousands of Holocaust survivors. Meanwhile, Greenspan has adopted a very different strategy. A colleague of his lightheartedly stated: "The Shoah Project wants to interview 50,000 different survivors once. Hank wants to interview the same survivor 50,000 times" (qtd. in Greenspan, 2010a, p. 1).

Greenspan claims that video-testimony encourages survivors to make declarative or unidirectional statements, such as "this I witnessed" and "this I believe" (Greenspan et al., 2014, p. 194). Although many individuals and institutions such as those listed above have recorded Holocaust survivors' testimonies, few have engaged these individuals as "partners in conversation" (Greenspan et al., 2014, p. 147). Greenspan argues that having regular dialogue and forming bonds with his collaborators allows them and him to engage in "learning together" (2010a, p. xii) and "knowing with" (2010a, p. 230). He takes time to build trust with witnesses, and works with them for sustained periods, often over many years. Greenspan claims that he is interested in learning about survivors' "wider life histories" (2010a, p. 153), and he assists them in representing themselves as unique individuals. He refers to relationships that emerge with respondents over time as a "working alliance" (2015, p.151), and insists that this is pivotal to the success of their collaborations. As a reflection of the collaborative nature of his work, Greenspan also describes the people he interviews not as "subjects" or "informants," but as "participants" who engage in "widening conversation" (2015, p. 7) with him.

Greenspan argues that video-testimony interviews are "highly structured," and that recorded interviews are edited in order to highlight specific types of information, omit content that he believes is important, and that many witnesses have found these "too controlling" (2004, p. 203). Survivor Ruth Kluger told Greenspan that her experience with video-testimony did not feel like a true conversation, and that the person who interviewed her seemed to take on a particular "pose" and "attitude" that felt unnatural to her (2004, p. 203). Diane Wolf adds that video testimony allows survivors to communicate only *parts* of their stories, and argues that the Shoah Foundation's methods are "formulaic," "romanticized," and "simplistic" (2007, p. 172). Noah Shenker claims that the Shoah Foundation and the Fortunoff Video Archive, as well as the U.S. Holocaust Memorial Museum in Washington, DC, which has also recorded video testimonies with survivors, have adopted practices that are not impartial and reflect their "institutional histories and methodologies" (2015, p. 3). In contrast to one-time video testimony interviews, Greenspan's method involves sustained acquaintance and collaboration with witnesses. He engages in face-to-face conversations, phone calls, email, and "off the record correspondences" (Greenspan et al., 2014, p. 221) with survivors. Kenneth Waltzer, who has built upon Greenspan's strategies in his testimony research with Holocaust survivors, explains that he found email and phone conversations with witnesses, after they had been interviewed by the Shoah Foundation and other organizations, helpful in order to create varied and subtle knowledge (Greenspan et al., 2014, p. 200).

Greenspan describes his approach as "recounting," and suggests that the term reflects the "provisional and processual nature of retelling" (2010a, p. 3). In video testimony, he insists, the goal is to encourage witnesses to communicate in one-way directions for viewers who simply "get" or "gather" (2010a, p. 3) information that has been conveyed. Greenspan rejects this model and asserts that survivors' stories emerge within the context of their dialogue with him, which often goes on for years and even decades. He emphasizes that responders and researchers engage in mutual inquiry, which he describes as "learning together" (2010a, p. xii) and "knowing with" (2010a, p. 230). According to Greenspan, this helps to generate knowledge about specific incidents and witnesses' stories more broadly. The intimate nature of the researcher-survivor relationship encourages survivors to examine memories that they may not have previously shared, consider decisions they made as the war unfolded and after it ended, and reflect on how the meanings of these recollections may have changed over time (Greenspan, 2010a, p. 203).

This type of relationship between interviewer and interviewee is not emphasized during interviews recorded by the Shoah Foundation, which has encouraged interviewers to maintain a "distance" (Shenker, 2015, p. 126) between themselves and witnesses. Individuals who have conducted interviews have been told that this would help them avoid being psychologically affected in negative ways by the stories they heard. Greenspan maintains that his professional role as a scholar is not affected when he allows himself to develop friendly connections and empathize with his collaborators. By developing human connections, he insists that he is able to contribute more as a researcher and support survivors in producing their testimonies.

Shenker contends that the Shoah Foundation has encouraged survivors to respond to questions about their most vivid recollections (2015, p. 128). He claims that this tactic was designed to obtain information that could contribute to or confirm other witnesses' memories. He adds that the organization felt this would be helpful in order to assemble a historical record that

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would preserve the memory of the Holocaust for future generations. In its quest, however, survivors were rarely invited to explore "fragments" (Shenker, 2015, p. 128) of memories that may have been more difficult to recall or perform while being video-recorded. In contrast, by engaging in dialogue with his collaborators over a lengthy period of time, Greenspan has invited witnesses to examine events that may be unique to them, not directly relevant to others, and memories that may be harder to recall.

As noted previously, Greenspan's communication with survivors takes multiple forms, including face-to-face meetings, informal get-togethers, telephone calls, and emails. Frequent communication allows his research participants to develop understandings about their experiences in unanticipated ways (Greenspan 2014, p. 200). This sense of spontaneity is different from what happens in more traditional interview settings, where some survivors describe having pre-planned speeches that they may have previously delivered in video-recorded testimonies, at schools, or museums. Survivor Agi Rubin calls this type of script the "usual spiel" (qtd. in Greenspan, 2010a, p. 229). She suggests that rehearsed presentations get stale, and that collaborative learning allows survivors to produce unique information. Recalling her work with Greenspan, she explains: "One thought sparks another, and then another, that I may not have even known I had. That is the part that is so gratifying. Whatever I imagine I'm teaching, I'm learning at the same moment. We're learning together" (qtd. in Greenspan, 2010a, p. xi).

Scholars such as Wolf have been inspired by Greenspan's attempts to explore Holocaust survivors' lives in deep and nuanced ways. In a 10-hour interview that she conducted with survivor Jake Gerldwert, Wolf invited him to discuss his life after the war. She discovered that many important parts of this period in his life had not been covered in an earlier interview that Gerldwert conducted with the Shoah Foundation. Gerldwert revealed that after he migrated to the U.S., his wife's family forced him to work in harsh conditions in their grocery store and prevented him from practicing his religion. Wolf maintains that the Shoah Foundation has presented Gerldwert and other survivors as heroes, but she claims that it is beneficial to learn about and share how respondents spoke about how they continued to suffer in the post-war period 2007, p. 171). According to Wolf, many of her interviewees stated, "My war began after the war" (2007, p. 172).

Research that involves producing collaborative and in-depth testimonies is challenging, fraught with ethical questions, and it is not always possible to achieve clear results (Greenspan 2015, p. 160). According to Greenspan, conflicts can arise between researchers and respondents,

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which is not surprising given the sensitive nature of the material that is often explored (2015, p. 161). In spite of these hurdles, the potential benefits of these methods make experimenting with them worthwhile. Although I did not work with my collaborators for years as Greenspan has, I attempted to replicate the same type of sustained and informal rapport that he has developed with his collaborators that has resulted in unique, creative, and compelling testimonies.

Greenspan's work has informed other scholars' testimony research with Holocaust survivors and other populations (Patti 2015; Ellis & Rawicki 2015; Sheftel & Zembrzycki, 2015). The *Life Stories Project* conducted by COHDS used modified versions of Greenspan's method. Researchers conducted multiple interviews with survivors of the genocides in Rwanda, Cambodia, and people who lived through other episodes of mass violence and rights abuses. Certain foundational texts in oral history, including *Doing Oral History* by Donald Ritchie (2015), recommend that scholars conduct at least three interviews with research participants, even though this is not commonly practiced in the tradition (H. Greenspan, personal communication, October 6, 2018). Anthropologists are accustomed to conducting repeated interviews with participants, as are professionals who practice therapy and counselling, which is the tradition that Greenspan was first trained in and practiced.

In spite of the benefits and tradition of multiple-interview research, given that Greenspan and other testimony scholars have primarily worked with survivors of genocide and mass violence, I considered whether it was appropriate for me to adopt his method of "recounting" (2010a, p. 227) in this project. Given that thousands of people across North America have died from drug-related overdoses, and that many of their loved ones have been significantly affected and silenced, I believed that Greenspan's approach was not only appropriate but vital in this context.

# **Personal resonances**

I was drawn to build upon Greenspan's Holocaust testimony research in this project, because the methods that he and other scholars have developed are valuable and transferable to researchers working with other populations. This field of research also has personal resonances for me, because my paternal grandmother, Gina Goodman, survived the Holocaust. As I write below, I frequently attempted to interview her about her wartime experiences. She was only willing to reveal parts of her past to me in one conversation that I managed to audio-record. When she died nearly 10 years ago, most of her memories of survival were lost. I continue to feel the weight of the fact that I will not be able to learn more about how her experiences growing up in Nazi Germany, and how ultimately fleeing the country affected her when she was young and after the war once she settled in Canada. The only consolation I have is that when she passed away, she left approximately two dozen pages of handwritten notes for me. She folded them in an envelope and wrote my name in capital letters on the front of it. I believe that she wrote these notes not long before she died, and she bestowed them to me because I had persistently tried to ask her about her past. When I learned that she had left these pages for me, and when I held them for the first time, I felt honoured and moved. I managed to decipher most of her Yinglish (i.e., a blend of English and Yiddish) handwriting, and felt both uplifted and devastated to learn a little bit more about events that she had kept secret for decades.

In my previous research-creation projects with people who use heroin in Vancouver, I aimed to represent my collaborators differently and more humanely than how photographers often do. After years working as a journalist and documentary maker, I was seeking more nuanced ways of telling stories with marginalized and stigmatized populations. By exploring and applying Greenspan's strategies, I have expanded my knowledge of research methods and will likely adopt them again as I engage in new studies with other individuals and communities. In the following section, I discuss some of the fist attempts to produce audio-recordings of Holocaust testimony interviews, and how this work later led Greenspan to recognize the benefits of having conversations in spontaneous ways and adopt this tactic in his own research. I highlight some of the innovative approaches that Holocaust testimony scholars have utilized that have been inspired by Greenspan's method, and examine some of the benefits and risks of their work.

# Other approaches to Holocaust testimony

Beginning in 1946, American psychologist David Boder, who was born in Latvia in 1886, recorded testimonies with as many as 109 Holocaust survivors (Illinois Institute of Technology, n.d.). He discovered that few people were interested in the material when a book that he published containing the interviews was received with little enthusiasm. In fact, his work was hardly acknowledged for decades and remains largely unknown. Yet, Boder was not the first person to collect testimonies of Holocaust survivors. By the time he launched his project, historical societies had conducted thousands of interviews with witnesses (Greenspan, 2015, p. 148). However, Boder was the first to create audio recordings of testimonies using a wire recorder. In many of these recordings, Boder's interview style comes across as rigid and rather strict. Instead of conversing with survivors, it sounds to me like he was almost interrogating these individuals. Boder delivers his questions in staccato fashion, leaving little time or space for witnesses to respond, and he allows for few pauses or silences. A particular interview that he conducted with 19-year-old survivor, Abraham Kimmelman, was transformative for Boder. By speaking with Kimmelman, Boder recognized the benefits of working in a more prolonged, unstructured, and "improvisational" (Greenspan, 2015, p. 149) manner, and this significantly affected his approach as he moved forward. Boder's willingness to listen and collaborate with Kimmelman, as opposed to simply collecting his testimony, signaled to other researchers that it is possible and even beneficial to work in participatory ways with survivors (Greenspan, 2015, p. 152). Greenspan adds that in spite of their affordances, collaborative approaches have been rarely adopted, and that "conventional ways of engaging survivors . . . have become so taken-forgranted" (personal communication, Oct. 8, 2018). He claims that this is likely because of "professional habits and paradigms, which recreate themselves more or less automatically" (personal communication, Oct. 8, 2018). Greenspan also encourages researchers to consider the advantages and drawbacks of employing a "multiple interview collaborative approach relative to single interviews" (personal communication, Oct. 8, 2018).

Carolyn Ellis is one of the scholars who has taken Greenspan's call for greater collaboration to heart, and has developed a participatory approach to working with Holocaust survivors that involves what she calls "interactive interviewing, and co-constructed narrative approaches" (Ellis & Rawicki, 2015, p. 171). Together with witnesses, Ellis explores their stories and writes narratives in which she amplifies significant emotional moments. Her goal is to help bring some of the most telling moments that survivors experienced to life for readers and explore moral questions that surface in these narratives. She has "co-constructed and mutually analyzed" eight short stories with Jerry Rawicki, a Jewish survivor who was a boy in Poland during the war (Ellis & Rawicki, 2015, p. 171). The narratives focus on instances when Rawicki managed to escape threats to his life (Ellis & Rawicki, 2015, p. 150). Like Greenspan, Ellis works over lengthy periods of time with her collaborators. During the writing process, Ellis and Rawicki were in regular dialogue with each other, engaging in what Ellis calls "collaborative witnessing" (Ellis & Rawicki, 2015, p. 172). She explains: "These stories involve months of daily back and forth editing, commenting, and decision making as we figure out how best to convey his experience and gain insight into its meaning" (Ellis & Rawicki, 2015, p. 172).

Critics could potentially argue that Greenspan, Ellis and others who work in collaborative ways with research participants skew the work that they mutually produce. According to Linda Shopes (2003) and Valerie Yow (1997), it is challenging for scholars and respondents to develop methods of working on projects together, to determine when to cede control and when to claim it, how to respect each other's varying objectives, perceptions, articulations, and how to ensure that power to make decisions is fairly distributed. In spite of these challenges, Ellis insists that her research, creative writing process, and the final stories that she produces reflect the trust, close listening, and compassion that she and her collaborators foster together (Ellis & Rawicki, 2015, p. 172-173).

Chris Patti served as Ellis' PhD supervisor and also uses collaborative methods. He practiced what he calls "compassionate listening" and "collaborative storytelling" with Holocaust survivor Sal Wainberg (2015, p. 194). Patti explains that his method was inspired by approaches developed by Greenspan, Ellis and Rawicki, and others. Patti and Wainberg developed a close friendship over many years, and he recorded several of their informal conversations (2015, p. 194). Unlike scholars who strive to maintain distance from research participants in order to remain objective, Patti believes in "cultivating compassion" and offering his work "as an intimate, vulnerable work of love" (2015, p. 196). He admits that his approach is not typical and even "risky" (2015, p. 195), because it is not the traditional way that scholars engage with research participants and does not require that he remain neutral. Patti describes his process as "messy, interconnected, relational, and always incomplete" (2015, p. 205). Engaging with Patti over a lengthy period allowed Wainberg to develop new realizations about key moments in his life. It also provided opportunities for Patti to "hear things not traditionally heard in oral history interviews" (2015, p. 193). Sustained and compassionate listening enabled him to develop a strong bond with Wainberg, who told him, as he was dying, "I feel as if one person has really listened, has really tried to understand. You have" (2015, p. 206).

# Limitations and risks of Holocaust testimony research

In this section, I address questions about the reliability, accuracy, and authenticity of Holocaust testimony and the contribution that survivors' narratives can make in spite of these claims. I highlight other challenges for researchers who engage in this work, including how it can be beneficial to invite survivors to reflect on all parts of their lives and not only about their lives before the war and during the Holocaust. I explore how witnesses are often exploited by scholars and discuss the risks of passive empathy, of labelling survivors as traumatized, and the potential to cause survivors to experience emotional upset.

# Reliability, accuracy, and authenticity

Christopher Browning suggests that people who lived through the Holocaust have created testimonies as a means of dealing with feelings of severe isolation, to re-establish links with the public, and to challenge the Third Reich's efforts to completely eliminate Europe's Jewish population (2003, p. 37-38). He adds that testimony has allowed survivors to examine how they have been emotionally and psychologically impacted by the Holocaust and to communicate their strength in the face of extraordinary challenges.

In spite of witnesses' intentions, the reliability and accuracy of their testimonies has sometimes been called into question. Browning stresses that survivors' testimonies need not be "factually" accurate. Instead, he argues, the "authenticity" (2003, p. 38) of witnesses' recollections is more critical. Rather than asking how survivors' testimonies, which are often "conflicting and contradictory" as well as sometimes "mistaken" influence public memory," he is more concerned with gathering "individual plural" and "collected memories" (2003, p. 39) in order to build the past that would otherwise be opaque because of a shortage of historical records.

Jewish Holocaust survivors' memories are not the only ones that have been contested. According to Browning, following the war, members of police squadrons that operated in Nazi Germany not only had difficulty remembering and altered their stories, some deliberately fabricated, downplayed, concealed, and pretended to not be able to recall their experiences and roles during the Holocaust (2003, p. 39). When it comes to Jews and members of other persecuted groups who lived through war, the use of their testimonies as archival documentation has been challenged to a greater extent than Nazi collaborators'. Some who argue that the Holocaust never took place claim that survivors' testimonies were extracted under duress following the war in order to support narratives that the U.S. and its allies were spreading about their victory. Others insist that Holocaust survivors intended to tarnish Germany's reputation, and to claim money the country offered to survivors (Browning, 2003, p. 39-40).

Browning rejects these conspiracy theories, but he accepts that witnesses' memories often do not align with others' when it comes to specific details, including "chronology, dates, persons, and events" (2003, p. 46). He adds that the recollections of 173 former prisoners of Nazi concentration camps at Starachowice in Poland allowed him to construct the history of the abuses that unfolded there over a period of nearly two years while it was operational as well as fine details about prisoner and perpetrator life (2003, p. 60). Browning recalls that he was prepared to find that survivors' memories had shifted, that witnesses might be unwilling to speak about particularly difficult experiences, and that survivors' recollections may have been influenced by others' memories (2003, p. 46). What he discovered, however, was that witnesses' recollections were intact and had not significantly changed. Browning notes that this led him to concur with Greenspan, who argues that even years and decades after the Holocaust, survivors are still able to offer accurate, reliable, and authentic information. Greenspan calls this "most noteworthy and remarkable" (2001, p. 20). Dori Laub argues that in spite of the widespread belief that witnesses' memories fade over time and that their testimonies become increasingly unreliable, he has found that as survivors age, many are able to communicate even more detailed and nuanced information (Greenspan et al., 2014, p. 199). He adds that this can lead witnesses to gain important insights about their own experiences and lives and to share these with others

Wieviorka explains that testimony has been used to document crimes of the Holocaust, particularly in cases where archival material does not exist (Greenspan et al., 2014, p. 209). However, as noted above, historians have questioned whether survivors' testimonies are reliable, accurate, and authentic, and whether they can be used in research. Berel Lang argues that witnesses' memories are subjective and change over time (Greenspan et al., 2014, p. 206). Janet Walker also urges scholars to be mindful of inevitable omissions or inaccuracies in people's memories, and calls on scholars to rebuild historical events instead of fully accepting people's recollections. She claims that "testimony is marked as subjective by the prominence of the autobiographical impulse" (2005, p. 190). In order to ensure historical accuracy, Lang (Greenspan et al., 2014, p. 206) and Waltzer (Greenspan et al., 2014, p. 208) agree that it is imperative to hold testimonies up against other forms of evidence. In instances when historical documents do exist, and even in cases when they do not, testimony has allowed people to share their voices and for their personal experiences to emerge. Laub adds that this can help educate the world about the impacts of genocide and aid in preventing similar events from occurring (Greenspan et al., 2014, p. 208). Wieviorka contends that survivors' testimony allows for "anthropological" documentation of the past, but adds that additional data is needed in order to understand the "political mechanisms" of history (Greenspan et al., 2014, p. 209).

Questions about whether survivors' memories change as they age and about the fundamental accuracy, reliability, and authenticity of their testimonies persist. According to Greenspan, these issues have not prevented him from collaborating with survivors, but instead have led him to view the work they have created together as part of a wider exploration and not one based only on "the facts" (Greenspan et al., 2014, p. 194). He recalls how a survivor named Leon, whom he began working with in the 1970s, told him that recalling "names, dates, and places" would not allow him to truly reflect on his lived experiences and the meanings that he has developed about them. "It robs us of what is most important" (Greenspan, 2010b, p. 11), he told Greenspan. Instead, Leon preferred to explore "philosophic[al] questions, all questions of purpose, of right and wrong, of justice, of God" (Greenspan, 2010b, p. 11). Similarly, Sara Horowitz insists that historians have traditionally been uneasy about utilizing survivors' memories in order to rebuild the events of the Holocaust, because they have been deemed undependable as archival material (Greenspan et al., 2014, p. 194-195). Like Greenspan, however, she argues that survivors' recollections and narratives are useful if one views them as "metaphor" and a valuable source of knowledge about issues such as "ethics, inner life, and the large human questions" (Greenspan et al., 2014, p. 194-195). In light of Hitler's attempts to erase the Jewish people from Europe, and the fact that there are few records of several instances of the mass-murder of Jews, Laub argues that the memories of individuals who lived through these events and their first-person perspectives are invaluable. He states: "For the Holocaust to be a real, informative event there has to be the voice of the 'I' who experienced it" (Greenspan et al., 2014, p. 207). Along these lines, while the Holocaust was taking place, many Jews urgently created hand-written archives meant to inform future readers about what was unfolding. Wieviorka calls these "a protest against death, a need to leave a trace to assure a legacy" (2006, p. 23).

John Peters claims that another reason why survivors' testimonies are often viewed as inaccurate, unreliable, and inauthentic has to do with the fact that their narratives are influenced by those who invite respondents to share their stories (2008, p. 710). Waltzer argues that it is inevitable that witnesses' memories will be shaped by the process of engaging in conversation with another person (Greenspan et al., 2014, p. 200). He adds that testimonies are affected by the motivations and methods of those asking questions as well as the issues that respondents choose to examine, how they decide to do so, and how much they are willing to disclose. Laub suggests that it is expected that testimony will reflect the nature of verbal exchanges that take place

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between survivors and interviewers (Greenspan et al., 2014, p. 217). He explains that the interviewer's interest in hearing what the witness has to say, combined with the listener's sympathetic responses and "emotional entanglement" (Greenspan et al., 2014, p. 217) with the person who is telling their story, are critical in order to produce important knowledge. Although some may claim interviewers can overly influence collaborators' testimonies, I believe that the role I adopted in this project did not lead to the production of inaccurate information. As testimony scholars mentioned above have argued, I think the connections that I shared with my interlocutors and the processes that we engaged in contributed to the depth and uniqueness of the narratives that hey created.

# **Periodicity**

Éva Kovács reveals that one of her greatest concerns about dominant forms of Holocaust testimony collection is that many questions that are posed and the narratives that are produced focus on specific periods, most often life before the war and during the Holocaust (Greenspan et al., 2014, p. 197). She argues that most testimony interviews and research fail to consider the fact that the Holocaust impacted virtually all areas and stages of survivors' lives. She explains that people who lived through the Holocaust often struggled for years and sometimes did not manage to adapt to life in post-war societies.

As mentioned previously, I attempted to interview my grandmother about her Holocaust experiences, but she declined to share very much information with me. It was clearly too painful for her, and she chose to keep what she had been through to herself. The silence that she insisted on maintaining until she died spoke volumes to me. I intuitively understood that the Holocaust had affected all aspects of her life, including her marriage with my grandfather, her relationship with my father and his siblings, my own connection with her, and more. I have reflected on whether I could have tried alternative strategies to encourage her to open up about her past, and whether I should have persisted like the filmmaker Abraham Ravett did with his mother in his film, *The March* (1999), which I highlight below. I held my questions about my grandmother's wartime experiences in my mind for many years, and only had the courage to ask her about these events a few times. While she was alive, I felt that her silence was impenetrable, and that nothing I could have done would likely have encouraged her to share her stories. Her refusal or inability to vocalize her experiences are understandable to me when I consider how Saul Friedländer stated "the Nazi past [is] too massive to be forgotten and too repellent to be integrated into the

'normal' narrative of memory" (1993, p. 3). In an autobiographical short story, survivor Ida Fink expressed:

I want to talk about a certain time not measured in months and years. For so long I have wanted to talk about this time, and not in the way I will talk about it now, not just about this one scrap of time. I wanted to, but I couldn't. I didn't know how. (1983, p. 3)

Recognizing how words cannot begin to describe the magnitude and suffering created by the Holocaust, Robin Linden asks: "Can deliberate silence be the only alternative to the narrative that belies itself?" (1993, p. 18)

Many survivors, including my grandmother, attempted to rebuild their lives in other places throughout the world. In doing so, many were too consumed with their new realities to focus on the tragedies they had experienced, not to mention how these could affect their familial relations and offspring in particular. In spite of their attempts to leave the difficulties they survived behind, Waltzer claims: "The past continued to recur in upsetting ways, including nightmares, sleeplessness, screams, sweats, and occasional phobias. The past was never absent" (Greenspan et al., 2014, p. 218).

Shenker points out that interviews conducted by the Shoah Foundation were structured in order to encourage survivors to speak about their lives in chronological order and in three key stages—prior to the war, in the midst of it, and after it ended (2015, p. 119). Greenspan is critical of this approach, because he asserts that these interviews often failed to sufficiently examine witnesses' life experiences after the Holocaust (Greenspan et al., 2014, p. 128-129). Rather than asking survivors to reflect on the meaning of events that took place once the war ended, interviewees were generally encouraged to deliver what Wieviorka calls "optimistic" (2006, p. 115) messages. Witnesses were often filmed with family members, including their grandchildren, if they had them. These scenes were deliberately constructed in order to communicate triumphant messages of survival for people who may watch the interviews in the future (Wieviorka, 2006, p. 115). According to Wolf, the Shoah Foundation has aimed to present Holocaust survivors as symbols of strength and hope (2007, p. 171). In contrast, Wieviorka indicates that testimonies recorded by the Fortunoff Video Archive were mostly "open-ended" (2006, p. 115), and interviewers were not trained to frame respondents as courageous and valiant. I concur with

Shenker who suggests that it is more interesting and beneficial to explore how the hardships people experienced during the Holocaust continued to affect them throughout their lives in an "entangled" as opposed to a "compartmentalize[d]" manner (2005, p. 128). Greenspan and others argue that this could help prevent interviewers from glossing over, avoiding, or failing to include details about specific and significant periods in survivors' lives, including after the Holocaust. As noted previously, my grandmother only spoke to me (and I believe others) about her wartime experiences in rare moments. In spite of her silence, I understood that she had been very courageous. I also saw her as complicated person, and that she suffered greatly because of what she had been through as a young person. Reflecting on my grandmother's experiences, I think it is helpful to try to understand the multiple long-term impacts of the Holocaust and to focus on survivors' resilience, and not to portray them as individuals who have completely made peace with the past.

In her research, Wolf has sought to explore how challenges that survivors endured during the war influenced them once it had ended. As noted previously, in her lengthy interview with Holocaust survivor Jake Geldwert, Wolf learned that some of the most evocative and painful experiences that he endured occurred after the war when he settled in the U.S. where his wife's family, who owned a grocery store, chronically abused him. In an earlier interview that Geldwert conducted with the Shoah Foundation, none of this material is acknowledged or vocalized, and Geldwert is framed as a hero. Wolf argues that the widespread omission of memories about life after the Holocaust occurred because those who conducted interviews were volunteers as opposed to professionals with wide knowledge of history (2007, p. 173). She adds that because the organization interviewed thousands of survivors, it resorted to using a "simpler approach" (2007, p. 173). As a result, according to Wolf, the testimonies that the organization has recorded reflect "partial and truncated views" (2007, p. 172) of survivors. This in turn, she suggests, presents "romanticized notions" of witnesses' lives in Jewish communities before the war, followed by oppression and mass-murder, and then ultimately their "redemption" (2007, p. 172).

What kinds of information are relevant to testimony research? Greenspan insists that it is important for him to consider "*everything*" (2010a, p. 4) as part of his process of collaboratively producing testimonies with survivors. Waltzer adds that he does not only consider his actual interviews with survivors, but he views the communication that takes place by email and telephone, often over long periods of time, to be important parts of testimony production (Greenspan et al., 2014, p. 200). He explains that witnesses may find it more comfortable to

express themselves in these ways, as opposed to in face-to-face dialogue with interviewers. He adds that sustained and informal conversation allows survivors to communicate new information and develop fresh insights.

Inspired by Greenspan's methodology, I remained open to any potential lines of inquiry and listened to everything my collaborators had to say. At the same time, I ultimately recognized that we would not be able to include all of the material they communicated and recorded in their testimonies in the digital memorial. However, I thought it was valuable to collect as much information as possible about a wide range of topics. I never encouraged the participants to recall their memories in chronological order, and I did not prioritize particular periods of their lives. I believe this allowed my interlocutors to examine a wide range of experiences from different times, which was ultimately helpful to us as we created the digital memorial.<sup>21</sup>

# Exploitation of witnesses and respecting participants' wishes

Many Holocaust survivors were initially reluctant to vocalize their experiences, and many lived out their lives hardly saying a word about what they had been through. Individuals who have given their testimonies have often done so in order to relieve themselves of the strain of keeping their pasts to themselves, to appease family members, and to share their stories more broadly (Wieviorka, 2006, p. 128). Despite these benefits of interviewing survivors, researchers, film producers, and others can exploit and "dispossess" (Wieviorka, 2006, p. 129) these individuals of their own narratives. Holocaust survivor Henry Bulawko spoke publicly about his experiences in concentration camps and took issue with how historians referred to him and other witnesses as "living documents." He said: "One can go from being a 'former inmate' to a 'witness,' then from 'witness' to 'document.' So then, what are we? What am I?" (Finkielkraut, 1994, p. 129). In my engagements with my collaborators, I always tried to ensure that they felt respected and had agency in the research and storytelling processes. By listening and assuming the role of facilitator, I found that the participants were consistently open to sharing their stories in a deep way. I recognized that their willingness to be vulnerable and speak openly allowed

<sup>&</sup>lt;sup>21</sup> Trinh Minh-ha argues that fragments of memory and testimony may appear to not form cohesive narratives, but they can allow "another world to rebuild . . . itself with its debris" (2009, p. 23). Documentary filmmakers including Claude Lanzmann, Joshua Oppenheimer, and Rithy Panh have used fragments of testimonies and shards of memories in exploring the Holocaust, the 1965-66 genocide in Indonesia, and the Khmer Rouge genocide in their films.

their stories to challenge dominant narratives about the opioid crisis and people who have experienced overdoses.

Other scholars have faced obstacles while working with participants who are not always willing to openly share stories. In their testimony research with Holocaust survivors, Anna Sheftel and Stacey Zembrzycki claim that they were interested in communicating stories that are not normally told (2015, p. 200). Like Greenspan, they were in search of subtle details that could form new types of knowledge (2015, p. 214). In order to do so, they attempted to listen intensively to a small group number of Holocaust survivors. However, they found that their interviewees were not always open to "speak[ing] deeply" (2015, p. 214). Sheftel and Zembrzycki recall that some of the witnesses they interviewed expressed reservations about examining certain areas of their pasts, because they felt they might lose control of their narratives as well as their power (2015, p. 202). Some said that exploring their personal histories in depth could mean saying that they were feeble. Certain witnesses added that they wanted to avoid presenting themselves in unsympathetic ways or admitting that they had perhaps conducted themselves in inappropriate ways.

Sheftel and Zembrzycki add that in inviting survivors to reflect deeply about their pasts, they were asking their collaborators to potentially disrupt how they have viewed and built meanings about particular events. They conclude that not all of the survivors were willing or able to do so (2015, p. 201). Sheftel and Zembrzycki reflect on how they continued to engage with their research participants in ways that they hoped would lead these individuals to feel respected and communicate new knowledge, but they indicate they had to agree to the terms that their participants set.

I saw my project collaborators as genuine partners. I would never have deliberately done anything that would have potentially made them feel uncomfortable. This does not mean that I did not ask difficult questions. I was always aware of the trust that we had developed, and I did not want to compromise that in any way. This meant being patient. In instances when I felt compelled to ask challenging questions, such as inviting them to speak with Michael in the present moment, I first considered whether it was appropriate to do so. I was fortunate that my collaborators never placed limits on what they were willing to speak about. They were also willing to experiment with all of the methods that I introduced. I recognized that the topics we covered were extremely difficult for them sometimes, and I tried to navigate this as sensitively as possible. If they had indicated that they were not comfortable speaking about particular topics, I would have respected their wishes. If this had occurred, I would have likely tried to continue building a rapport with my collaborators. If the situation did not improve, I might have considered exploring the possibility of collaborating with other research participants who were more willing or able to make the type of contributions I was searching for.

## **Re-examining the notion of trauma**

Laub utilizes a psychoanalytic perspective and claims that drawing on trauma theory is helpful in his testimony work with Holocaust survivors. He describes individuals who lived through the Shoah as having experienced "extreme human pain" and "massive psychic trauma" (1992, p. 57). Kovács states she has found it helpful to consider how Holocaust survivors have experienced trauma and how it has been passed down to their children and grandchildren (Greenspan et al., 2014, p. 222). However, Greenspan and other testimony researchers argue that some scholars place too much emphasis on trauma in their work. For his part, Greenspan encourages researchers to avoid approaching interviews as "lay counselling" and refrain from using terms such as "trauma" and "post-traumatic stress disorder (PTSD)" to describe or label survivors (2010a, p. 257). Unless they are psychologists, he insists that most researchers do not have sufficient training or knowledge to accurately or ethically use these terms.

Greenspan argues that employing the word "trauma" to describe survivors' experiences is too general of an approach. He claims that if the term is used "with precision," it can be "an enormously useful concept." But he cautions that if it is used "as a synonym for all psychological aftereffects, catastrophe, atrocity, and even genocide, we lose track of trauma's particular horrors as well as its relationship with other different agonies" (Greenspan et al., 2014, p. 215).

Greenspan explains that humanities and social science researchers began to widely use the term "trauma" in the late 1970s and early 1980s, in part because of the emergence of the 'narrative turn' in these fields. At the same time, post-traumatic stress disorder (PTSD) was officially recognized as a psychiatric condition. Both of these developments led journalists to embrace the word, and many continue to use it liberally today. However, Greenspan claims that the "preoccupation with trauma" in testimony work leads researchers to represent people as beings who live in "extremity," which can conceal how many survivors continue to live with strength, in spite of the challenges they have faced (Greenspan et al., 2014, p. 220). He explains that labelling people as "traumatized" suggests that these individuals are unable to create change in their lives, and are in a state of "paralyzed shock" (2015, p. 142). Susan Brison argues that

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according to most psychologists, trauma implies that "a person feels utterly helpless in the face of a force that is perceived to be life-threatening." She adds: "The immediate psychological responses to such trauma include terror, loss of control, and intense fear of annihilation" (2002, p. 38). Similarly, Horowitz suggests that referring to survivors as "traumatized" robs people of their agency and implies that they should be "cured of memory" and "move on" in order to become "whole again" (Greenspan et al., 2014, p. 221). Lang suggests that it is difficult to precisely point to how trauma affected survivors' lives after the war, and that as a result, it is best to avoid trying to do so (Greenspan et al., 2014, p. 216).

Greenspan insists that through sustained collaboration, testimony researchers can come to understand and help communicate the nuances of survivors' lives and ultimately see them as far more than traumatized (2010a, p. 221). He reflects on the fact that survivors have often lived through a range of experiences, including "abandonment, isolation, desolation, degradation, humiliation, all the physical agonies . . . deprivation, hunger, exposure . . . helplessness to help others . . . [and] loss and grief . . ." (2015, p. 143). After all, Greenspan explains, these individuals are still alive, often in the absence of their loved ones and communities (2015, p. 143).

Salverson adds there is also a tendency among playwrights, actors, and directors to privilege trauma. She refers to this as an "aesthetic of injury," which she defines as "an overly tragic approach which does not allow for the "saying" of loss but instead fixes trauma in presumed configurations of how loss looks like" (2001a, p. 194). Salverson explains that stories that highlight "melancholic loss" frequently neglect other elements of stories that are often alluded to but not examined in great depth on stage. She asks:

But why is the pain of injury considered more accurately translatable, more faithful to grief, than the terrain of laughter, of the imagination, or the pleasure of encountering another person in the touching of worlds that is testimony? These are also elements of living the stories of loss. (2001b, p. 124)

In light of the complications with using the term "trauma" in testimony research, I have made a conscious choice to avoid this language in this thesis when referring to Michael, my collaborators, myself, and others. Rather than utilizing the word "trauma," I have opted to use language such as "challenge" and "difficulty," which does not erase the fact that people may have faced obstacles, but also does not suggest that individuals permanently lack agency and cannot lead full and productive lives.

### Emotionally or psychologically upsetting witnesses

When it comes to working with vulnerable individuals and communities, there is a risk of causing them to become emotionally or psychologically upset. For certain documentary filmmakers, this has not been a major concern. Some directors have been more interested in obtaining detailed and rarely articulated information. For instance, Claude Lanzmann spent more than 10 years making *Shoah* (1985). He deliberately chose not to use any archive footage in the film, and instead relied on filming testimonial interviews with survivors, perpetrators, and witnesses (Felman, 2000, p. 106). His approach was intended to reawaken audiences to the atrocities that the Nazis were determined to conceal (Felman, 2000, p. 104). In his role as "interviewer", and "witness," Lanzmann insisted on interrupting the silence that persisted in the decades following the Holocaust. He pressed witnesses to reveal specific and often painful details as opposed to offering generalizations or impressions. "From the station to the unloading ramp in the camp is how many miles?" (qtd. in Felman, 2000, p. 118), Lanzmann asked a survivor in the film. "Exactly where did the camp begin?" (qtd. in Felman, 2000, p. 118).

Shoah helped inform the world about the Nazi crimes, but Lanzmann's approach raises a number of ethical questions (Young, 1998, p. 168). For instance, in a scene with Abraham Bomba, a survivor and former barber, Lanzmann questioned him as he cut a man's hair in a rented barbershop in Tel Aviv. Bomba had been forced to cut women's hair, including the hair of some of his female family members, before they were killed in gas chambers at Treblinka. In the film, Bomba paused and is clearly upset, but Lanzmann implores him to speak: "How did it happen when the women came into the gas chamber? . . . What did you feel the first time you saw all these naked women?" (qtd. in Felman, 2000, p. 118). Bomba responded : "I won't be able to do it. . . . Don't make me go on please" (qtd. in Felman, 2000, p. 119). In spite of his requests, Lanzmann asked him again, this time more forcefully: "We have to do it. You know it. . . . *Please*. We must go on" (qtd. in Felman, 2000, p. 119). In the end, Bomba complied, and through tearful testimony revisited some of his most difficult memories.

Nora Levin argues it is possible to cause witnesses to suffer in significant ways by demanding they re-imagine difficult situations and experience challenges again. She states: "I

could not forgive Lanzmann's insistence on pushing survivors to a degree of torment that was unbearable, beyond that delicate line which they themselves had defined" (1986, p. 91). In the the scene with Bomba outlined above, it is clear that Lanzmann used his authority as a director with unabashed intensity. As a result, Bomba spoke and shared details of his Holocaust experiences, and his testimony is now part of the public record. Lanzmann (2005) later claimed that Bomba's tears were "worth gold" (2005). He argued that the most critical witness testimony has to do with what took place in the gas chambers. In contrast, Marianne Hirsch and Leo Spitzer claim "the silence and muteness are more telling and forceful than verbal narratives" (2009, p. 158).

Other filmmakers have been indefatigable in their quests to uncover survivors' pasts and encourage them to speak about their Holocaust experiences. As noted previously, for over 13 years, Abraham Ravett filmed himself asking his mother, Fela Ravett, to recall her experiences surviving the Death March at Auschwitz in 1945. In *The March* (1999), Ravett appears obsessed with recording his mother's testimony. Toward the end of the film, even after his mother has had a stroke and is dying, Ravett continues to question her. She urges him to stop, using the word "overdo" (qtd. in Ravett) to characterize his relentless filming.

Ravett's tactics are nothing like those I adopted with my grandmother. I asked her to recall her past a few times, and she almost always said no. I was always concerned about potentially upsetting her, and I knew she would not be easily be convinced to open up. I waited for what felt like opportune moments, always considering her mood and the situation. I felt determined to find out about her past, because I sensed that what she had been through had shaped her life and mine in significant ways. However, I was not prepared to disrespect her and press on with my questions when she clearly had said she was not willing to talk. If I had acted like Ravett had and been more persistent, I do not think my grandmother would have spoken in greater depth. In the context of this project, as noted above, I never felt there were questions that I could not ask my interlocutors. I believe that our positive research-participant relationships, and the trust and respect that I felt we had for each other, allowed them to convey personal information in their recordings and our discussions, and I am grateful for that.

### Commodification, voyeurism, and cultural colonialism

We are living in an era in which testimony production has become increasingly common, yet scholars point to a number of risks associated with the practice. When it comes to Holocaust

testimony, one of the best known examples is the graphic novel, *Maus*, by American artist Art Spiegelman (1986 [1991]). The work is based on the testimony that his father shared with him about his Holocaust experiences. It is now one of the most widely recognized creative examinations of the Shoah and has been highly commodified through extensive multimedia marketing, exhibitions, and publication in a range of formats, including broadcast media and a comic strip (Rothberg, 2000, p. 244). Other depictions of the Holocaust, including the film *Schindler's List* (1993), directed by Steven Spielberg, and its musical score, have also become commodified (Rothberg, 200, p. 244). These two examples raise questions about the effects of commodifying stories related to episodes of mass violence and the potential to dilute or alter the meaning and impact of original testimonies.

Even if testimonies are not commercially commodified, they risk being claimed by powerful agents or filtered through particular lenses. Lisa Taylor, Unwalli Sollange, and Marie-Jolie Rwigema point to scholars who have outlined how Eurocentric academics and institutions have colonized and commodified historical narratives produced by indigenous peoples (Young, 1990 [2004]) and devalued oral history (Callison, 1995). The authors write:

Historians or students of history are never objective, neutral, or outside these power relations: they are separate from neither the object of study nor the institutional processes of constructing and defining that object within larger knowledge formations of academic or popular history. (2015, p. 89)

Gayatri Chakravorty Spivak argues that colonialism within academia and research leads individuals and institutions with power to wield what she calls "epistemic violence" (1988). In doing so, they are able to create a hierarchy in which some people and communities are deemed more worthy of having opportunities to articulate their experiences (Taylor, Sollange, and Rwigema, 2015, p. 89). When it comes to the 1994 Rwandan genocide, Taylor, Sollange, and Rwigema question whether the power dynamics that have been established within educational institutions have impacted the way knowledge has been produced and whose voices are recognized. They ask how the hierarchy of power within academia influences the ways that personal narratives about episodes of mass violence are "produced, represented, and engaged as objects of study" (Taylor, Sollange, and Rwigema, 2015, p. 90). The questions they pose are relevant for testimony scholars working with virtually any marginalized populations. They include:

What is presumed to be learned, by whom, from whom, for whom? Whose sense of history and whose agendas implicitly structure how testimony is selected, presented, and received? What affective dynamics are disavowed, indulged, consoled, or considered in institutional settings? (Taylor, Sollange, and Rwigema, 2015, p. 103)

How then can testimony scholars bear witness to people who have experienced significant challenges and assist them in communicating their experiences without engaging in cultural colonialism or voyeurism? Salverson argues that one way of mitigating these risks is to ensure that the "voice of the artist/educator" is examined (2001a, p. 8). When it comes to this project, I feel comfortable with the degree to which I have explored my position as a researcher and highlighted elements of my personal life. Salverson adds that in theatre, another way to reduce the risks of cultural colonialism and voyeurism is to challenge the distance that often arises between "the watcher and the watched" (2001a, p. 119). By describing a case in which an actor plays the role of a refugee, Salverson suggests that the spectacle can become voyeuristic, unless there is the sense that the refugee "turns to encounter the gaze of the actor/playwright/audience, demands our presence in the process, and names the illusion of representation" (2001a, p. 120). I take this to mean that in the context of a project such as mine, it is vital that witnesses not only perform superficial or rehearsed roles, but that they truly engage in conversation, inquiry, and production with the researcher. I believe the level of interaction and engagement that I had with my interlocutors allowed us to ensure that the project did not become an act of cultural colonialism or voyeurism.

# **Cultural expectations**

Greenspan insists that the manner in which testimonies are produced and the information that is transmitted are influenced by a range of cultural factors. One of the most influential elements is how survivors think of those who will or may listen to their statements (Greenspan, 2010a, p. 42). Robert Kraft refers to this phenomenon as "narrative expectation" — the anticipation of being asked questions that will invite them to share information that people want to learn about (qtd. in Cohen, 2014, p. 94). Greenspan explains that it is difficult to determine whether or how individual witnesses will modify their testimonies based on their perceptions of listeners (2010, p. 43). In some cases, he argues that survivors try to share details that they think those who are listening will be interested in hearing. He adds that witnesses sometimes feel ambivalent about the hopes of their listeners, and use their testimony "to challenge—indeed, to protest—their listeners' presumptions (2010a, p. 43).

One of the most common issues that influences the nature of Holocaust survivors' testimonies is the fairly common sense of guilt that many witnesses feel for having lived through the destruction when so many of their loved ones, and often their entire communities, perished (Greenspan, 2010a, p. 43-46).

In the decades following the Holocaust, Greenspan explains that many survivors did not publicly share their stories. He claims that many were reluctant to recall what they had been through because they felt "isolated" (2010a, p. 47) and "silenced" (2010a, p. 48). Greenspan adds that for many years, publics were not "ready to hear" and survivors were also "not yet ready to speak" (2010a, p. 48). Recalling their experiences during the Holocaust meant revisiting difficult emotions, but also risking what Greenspan's describes as "listeners' misunderstandings, resistance, and sometimes, outright rejection" (2010a, p. 49). In spite of these issues, many survivors chose to recount their wartime experiences, because as Primo Levi argues, even before the end of the war, the desire to share was "an immediate and violent impulse" (1996, p. 9) and "a primary need" (qtd. in Camon, 1989, p. 42).

Following the establishment of the Presidential Commission on the Holocaust in 1978, which led to the construction of the U.S. Holocaust Memorial Museum, a growing number of Holocaust survivors began to share their testimonies. Awareness about the Shoah also began to grow in the U.S. (and arguably, in Canada) after a mini-series, produced by NBC, titled *Holocaust*, was broadcast, and millions of people tuned in (Greenspan, 2010a, p. 60). During this period, Greenspan claims that American culture influenced the way in which publics hoped to hear stories of Holocaust survivors. Above all, he insists, they were interested in narratives that prioritized a trajectory in which the heroic emerged out of "the ashes" or "the darkness" or "defeat" (Greenspan, 2010a, p. 63). He claims that citizens yearned for stories that accentuated triumph and "the joy of survival" (Greenspan, 2010a, p. 63). Greenspan argues that the societal motivation to make heroes out of survivors and applaud their acts of speaking out meant that

frequently the details of people's individual narratives were overlooked (Greenspan, 2010a, p. 64).

According to Greenspan, some survivors hoped that by communicating their wartime experiences, the world would pay attention and listeners would comprehend them. He suggests that there was hope that the "world, somehow, would change" (2001, p. 14). Greenspan adds that as years passed, many witnesses adjusted their expectations. I suspect that one of the factors is that it appears that no matter how much awareness is created about the Holocaust, anti-Semitism continues to proliferate.

# Conclusion

In this chapter, I examined Greenspan's method of collaborative testimony research with Holocaust survivors. I highlighted a number of other scholars' innovative methods of working with witnesses in order to gather and disseminate their testimonies. I discussed my grandmother's personal history as a Holocaust survivor, which led me to develop an interest in testimony work. I explored some of the limitations and risks of this research and re-examined the notion of trauma in the context of Holocaust testimony. I also examined commodification, voyeurism, and cultural colonialism in testimony research, and some of the cultural expectations that Greenspan argues have influenced testimony work with Holocaust survivors.

In Chapter 4, I highlight how a few participatory and interactive projects that prioritize audio testimonies confirmed to me and my interlocutors that using audio testimonies as the foundation for the digital memorial that we constructed was an appropriate strategy. I discuss how my collaborators recorded their narratives and outline our process of communicating with each other. I explore how I originally invited the participants to respond to a series of written questions, and how they ultimately opted to record their testimonies by focusing on their experiences and emotions in a spontaneous way. Thereafter, I explore what I consider to be breakthroughs and nuanced information in their recordings, and discuss how this material resists dominant narratives about the opioid crisis and individuals who have experienced overdoses. The chapter ends with an examination of how I incorporated the concept of crafting grief and continuing bonds theory in the project, and how doing so helped my interlocutors reflect on their recordings.

# **CHAPTER 4**

# **RECORDING AND ANALYZING TESTMONIES**

# Introduction

In this chapter, I examine a select number of participatory and interactive projects focused on social issues that use audio testimonies in critical ways. I discuss how reviewing these initiatives allowed my interlocutors and me to conclude that producing audio narratives was a suitable and helpful strategy for our work together. I explore how the participants technically recorded their testimonies and outline the frequency of our exchanges. I highlight how I initially sent the participants writing prompts and invited them to respond to them, and how my collaborators ultimately recorded testimonies that focused on their experiences in an impromptu manner. Thereafter, the chapter features a detailed analysis of the participants' recordings. This section begins with a discussion of I view my interlocutors' testimonies as counter-narratives. I provide highlights of how two test listeners also view the recordings as disruptions of dominant ways that journalism organizations represent people who experience drug-related overdoses. I then examine how I introduced Hedtke and Winslade's concept of crafting grief and Hedtke's continuing bonds theory into the project and encouraged my collaborators to engage with these ideas. I explore how experimenting with these concepts allowed the participants to produce personal and nuanced narratives and reflect on their processes of creating their testimonies. I also explain how this process allowed them to create nuanced knowledge about the opioid crisis and the impacts of fatal overdoses for decedents' loved ones. The chapter ends with a deeper analysis of the participants' recordings. In this section, I discuss how I revisited my interlocutors' testimonies with them in telephone conversations, and invited them to share further reflections about the content of their recordings, their motivations for sharing the information they did, and if they felt the way our methods allowed them to feel supported in communicating their stories. I also share some of my autoethnographic reflections that were generated by listening to the participants' recordings and considering my personal responses. My written autoethnographic reflections are brief. Some are just a few sentences. Yet, they point to emotions and memories that allowed me to have a sense of empathy for my collaborators. The process of creating these reflections also enabled me to gain greater clarify about my own experiences in relation to my mother and my grief.

# **Technical process of recording testimonies**

From the outset of the project, I intended to build upon Greenspan's method of collaborative testimony production, which I believed was an optimal way to access counternarratives about the opioid crisis and people who had lost a loved one to an overdose. Unlike Greenspan, I did not have years to work with my collaborators. The time frame for the fieldwork of this project was a year. Nevertheless, I needed a way to engage in semi-regular dialogue with the participants on a one-one-basis and create audio-recordings of these conversations. I needed to then listen to the recordings as well as analyze, edit, curate, and disseminate them through the digital memorial that we would produce, all the while involving the participants in all aspects of the processes.

My collaborators could have produced written testimonies and communicated their memories and experiences in a range of ways, but we decided together that audio recordings were appropriate for the project and that these would form the foundation of our work. We also agreed that we would build a digital memorial in order archive and disseminate their testimonies, and that we would also use photos and minimal amounts of text. In conceptualizing the project, I examined a number of interactive projects that use audio testimonies in compelling ways. My collaborators also asked me to share for examples of work that had been created using audiorecorded testimonies and interactive technology, and I was glad to share these projects with them. Examining projects of this nature helped to confirm my view that audio is the most intimate medium (McHugh, 2012). It is for this reason that it has been widely adopted by oral historians and journalists.

The first project that I shared with the participants is an audio documentary produced by *This American Life* titled *Really Long Distance* (Meek, 2016). I first heard the 22-minute story as a podcast and felt moved by it, as I suspect many other listeners have. The documentary features the voices of survivors of the 2011 Tohoku earthquake and tsunami in Japan. The recordings that were repurposed by *This American Life* were initially made by Japan's national broadcaster, NHK. A resident just outside the disaster zone installed an old telephone in his garden, and people used it to deliver audio messages to relatives who had perished. It came to be known as the "wind-phone," because it was not linked to a real phone system. In the episode, children, adolescents, and adults leave tender and courageous messages for their relatives. Listening to their stories, the busyness of my life seemed to cease. As I heard their voices, I had the impression that I was next to them, even though they were on the other side of the world. I was

reminded of the power of audio to not only convey information, but to move masses. When I watch video, I often lose track of what is being orally communicated as I consider the images that are presented. When it comes to audio storytelling, I find I am able to concentrate on people's voices, and my imagination helps create pictures in my mind that are connected to the messages that are being delivered. This is what I experienced while listening to the evocative testimonies of people who shared their stories in *Really Long Distance*.

I also shared a small number of participatory interactive projects that I previously outlined in this thesis. The first initiative that I sent the participants is The Quipu Project (Lerner & Court, 2015), which I refer to in the Introduction and Chapter 2. I was interested in sharing how its producers used audio testimonies in innovative ways, and how these recordings are housed and shared via an interactive website. In order to listen to participants' recordings, users have the option of clicking on virtual representations of traditional Inca weavings known as quipu. These were part of an ancient Incan system of "record-keeping" and communication created by "tying knots and coloured threads" (Tucker and Brown, p. 2). I also shared the interactive project 86 1/2 Years (Usborne, 2017) with my collaborators. It uses audio testimonies and photographs in order to communicate the story of one man, Joseph Marcovitch, an elderly resident of East London. The project was produced by Martin Usborne, a photographer, writer, and co-founder of Hoxton Mini Press. As previously noted, Blood Sugar, created by Sharon Daniel (2010), is an interactive project that features audio recordings of women who currently or formerly used drugs and are incarcerated in California. Along with audio recordings, Blood Sugar (Daniel, 2010) uses graphics and text. Although it does not include any photographs, it presents the women's stories in a unique way. I invited my collaborators to explore this project and others that prioritize audio that have been curated by the MIT Open Documentary Lab (n.d.b).

My collaborators examined these projects and agreed with me that using audio narratives in an interactive project was an appropriate strategy for our work together. I then devised a way for the participants to produce audio recordings and send them to me. This approach was partly inspired by how *The Quipu Project* (Lerner & Court, 2015) functioned. I was initially able to provide my collaborators with a toll-free number that they could dial anytime and leave confidential messages of any length. Audio files of their recordings and transcriptions were automatically sent to an email account that I set up for the project. It seemed like an ideal and efficient way to proceed. I planned to listen to the recordings and respond with my impressions and questions by phone or Skype with Rose and Carina, and by email to Andréa. I thought this would allow us to engage in semi-regular dialogue, but I quickly discovered the technical quality of the voicemail recordings stored on the virtual voicemail system was not adequate for the digital memorial. The testimonies that were generated for *The Quipu Project* (Lerner & Court, 2015), were recorded on phones in rural villages in Peru, so the compromised audio quality of these recordings is as one might expect. The voices of the women in Peru sound distant and the phone line is grainy. For my project, however, it was important to me that the women's recordings came across as clearly as possible in order to enable users to feel as closely connected to my interlocutors as possible.

At first, Rose expressed apprehension about audio-recording testimonies on her own. I had shared some writing prompts and questions with her by email, but she said she preferred that I ask her questions in face-to-face conversations. Since she was in Toronto and I was in B.C., we opted to have semi-regular conversations on Skype. Rose used an iPhone and recorded our calls using a microphone that she connected to her phone as well as a tripod that I provided, and she emailed the audio files to me. This worked very well for both of us. We typically met on Sunday mornings, and I found that during our conversations, Rose was very focused and willing to share information about her connection to Michael, as well as her grief and other emotions.

Carina indicated that she wanted to write journal entries and audio-record them for the project. As noted in the introduction, I had read her *Lion's Roar* article (Sperry, 2017) about Michael's passing and his bipolar disorder. I recognized that she was a skilled writer. Her prose was honest and unembellished. I believed that her testimonies would be equally compelling, and I looked forward to listening and sharing her recordings through the project. In the end, Carina mostly recorded her testimonies in a spontaneous way using her iPhone and a microphone that I provided, and they were technically seamless and she always sounded at ease. After Carina emailed her recordings to me, I listened to them and responded to her by email. The purpose of doing so was to acknowledge what I had heard, offer some short questions aimed at encouraging Carina to continue reflecting on her experiences, and invite her to produce further recordings if she wanted to.

Andréa did not have access to the internet from her home in a relatively remote part of Mexico. Early on in the project, we had a couple of Skype calls, but this required her to travel half an hour to a friend's house, and this was not an ideal or sustainable option. We also tried speaking by phone, but even with a long-distance plan, the cost of the calls was prohibitive. This

led Andréa to record her testimonies on her iPhone with a microphone that I also sent her, and we had follow-up exchanges by email.

### Frequency of recordings and conversations

From the start of the project, I was mindful that I was inviting my collaborators to collaborate with me at time when they were facing significant challenges and time constraints. We initially agreed that they would record testimonies once a week, or every other week for six months. Yet, I recognized early on that this was an unrealistic goal, and I had to adjust my expectations. I was asking the participants to record their testimonies just months after Michael's death and their emotions and grief were still raw. Beyond that, each of the women had their own responsibilities outside of the project. In the end, they recorded their testimonies and engaged in conversations with me at different paces over the course of a year.

I had the greatest number of conversations with Rose, as previously noted. I never counted the number of hours that we spent talking, but we were ultimately able to curate and edit these audio-recorded discussions into 13 distinct recordings.

Carina gave birth to her and Michael's third child during the project, and this understandably occupied much of her attention. During her pregnancy, Carina also had to take care of her two other young children and attend to countless household duties. For these reasons, I never felt it was appropriate to add pressure and ask Carina to spend more time on the project or produce more recordings than she was willing or able to. She needed to work at her own speed and shared roughly one recording per month. At times, I questioned whether we would have enough audio material by the end of the project. However, the depth and openness of Carina's communication in her recordings allowed me to trust the process. Prior to agreeing to take part in the project, Carina took time to consider whether it was something she truly wanted to do and if she had time to commit to it. I sensed from the start that she had a great deal of integrity, and once she indicated she was interested in participating in the project, I believed she would deliver on her promise to share her story. After receiving Carina's first recordings, I knew that no matter how many times she recorded herself for the project it would be sufficient and that her contribution would be very rich. At the end of our collaboration, Carina had made seven recordings, adding up to nearly three hours of content. Given the profound and intimate nature of her testimonies, there was an abundance of material for us to work with.

As noted previously, Andréa was in Mexico and geographically the furthest from me. This did not prevent her from making a significant contribution at roughly the same pace as Carina. Just like my other interlocutors, I have not met Andréa in person, and I am grateful that she trusted me by making her recordings. Andréa also had a number of other commitments during the testimony recording phase, including planning her wedding and receiving a number of guests at her home. She took a brief break from the project during that time, but later enthusiastically recommitted herself to the work. By the time we finished the project, Andréa had created five recordings, amounting to over 1.5 hours of content. Altogether, we were able to edit the participant's recordings into 17 individual audio segments that each focus on unique themes.

# Analyzing the recordings

In this section I shed light on how my collaborators and I initially came up with a series of questions and writing prompts aimed at encouraging them to share their personal stories about their connections with Michael, their memories of him, and their grief. I provide details of how my interlocutors and I view their audio-recorded testimonies as narratives that challenge dominant ways of communicating about people who use drugs and experience fatal overdoses and silence decedents' loved ones.

#### **Creating counter-narratives**

In the first weeks of the project, my collaborators expressed to me that they were not sure how to start their recordings. They indicated that they were not clear about what they could talk about and share. The field was wide open, but I needed a way to help them to focus on themes that were relevant and timely to them. I wanted to encourage them to examine their individual connections to Michael and how his death had personally affected them, but I recognized that the participants needed some guidelines.

My interlocutors asked me to send them some questions that might help them focus their recordings. I emailed them a number of words that I had come up with, such as "family," "love," "mental health," "suffering," "labels/stigma," 'dying," and "promises" (personal communication, Nov. 28, 2017) Carina shared some additional words that resonated with her, including "alone together," "relief/options," "continuing," and "pain/suffering/patterns" (personal communication, Nov. 29, 2017). I thought these were excellent suggestions, because they seemed to reflect

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Carina's personal experiences. She asked me to also write additional questions that corresponded with the words. I was happy to do so and sent them to my interlocutors, hoping it might assist them in their writing and recording processes. For example, when it came to the topic of 'labels/stigma', I asked: "Were you and Michael affected by any labels or stigma?"; "What was this experience like for you and Michael?"; "Are there any difficult moments that stand out to you? If you could transform these moments, what would you do?" I came up with the following questions for the theme of 'love': "What did you learn about love through your relationship with Michael?"; "Was love easy?"; "What were some of the challenges?"; "What do you think about love now?", and "How do you continue to love Michael?" (personal communication, Nov. 30, 2017).

I made a conscious effort while formulating these questions to write them in ways that I hoped would encourage my collaborators to share information not only about challenges they were facing, but also about things they may have considered to be positive. In my questions about 'relief/options', I asked whether Michael had used drugs in an attempt to find relief, but I did not think it was critical that we investigate this issue. I did not want to deny that opioid use was part of the story and had contributed to Michael's death. Yet, I was more concerned with sharing deeper stories about who Michael was and how he impacted my collaborators' lives. Carina informed me that she felt betrayed by certain journalists because of the way they had framed Michael's death. She added that she felt some of the reporting about his passing had been "sensational" (personal communication, April 12, 2018). In her view, many reporters had presented Michael as a someone who died from a drug-related overdose without exploring his accomplishments and strengths in a substantive way. In my writing prompts, I invited my collaborators to talk about Michael's bipolar disorder if they wished. I felt that doing so could potentially help them challenge dominant narratives about individuals who have experienced fatal opioid overdoses. I thought it could also assist Carina and the two other participants' in making connections between Michael and the need for early intervention programs for people with mental illness.

In my written questions, I also encouraged my collaborators to reflect on their phenomenological experiences in their recordings. I asked them to reflect on their thoughts and feelings, as well as what they saw, heard, tasted, and smelled. I recognized that this is an established ethnographic practice that can assist writers in developing insights about their experiences and sharing this knowledge with others (Van Manen, 2016). Over the year, my interlocutors shared personal, emotional, and compelling recordings with me. In what follows, I describe some of the issues that they explored and how I view their recordings as counter-narratives. I also include some of the participants' reflections on how they thought their narratives are different than how journalism organizations typically report on the opioid crisis and people who are impacted by it.

#### Carina's recordings as counter-narratives

Two days before Christmas and two weeks before Carina was scheduled to deliver her baby, she sent me a recording that she titled *Life and death*. It was 34 and a half minutes-long and completely improvised. She had not written any notes before creating her testimony and this made it feel vivid and compelling to me.<sup>22</sup> In her recording, Carina recalls the night she learned that Michael had been found unconscious in Victoria. She describes watching the police officer approach her front door, lighting their way with a flashlight, and telling her that Michael was in hospital. In her recording she says: "I just remember them saying he was unresponsive and I just remember asking, 'What does that mean? What does that mean?', even though I knew they were saying he wasn't going to be okay" (Dec. 23, 2017).

In the recording, Carina also recalls how she then took a police boat to the hospital in Victoria where Michael was on life support. She explains how his lungs and kidneys were donated and how she walked the hospital hall feeling a sense of peace as his organs were removed. She recalls how the medical team told her they were having difficulty removing Michael's wedding ring from his finger, but eventually managed to do so. She adds how she had to exit the hospital down a flight of stairs that opened up into a dark and unfamiliar place, and how her father picked her up and brought her to his home where her children were sleeping. Throughout her recording, Carina's voice is steady, but it quivers slightly when she refers to her kids. Although some family members and friends have publicly shared details about how they have experienced loved ones' overdoses, dominant media organizations rarely leave space for this kind of information. The repetitive visual tropes of slumped-over bodies in alleys and vehicles do not communicate anything about how people who are connected to decedents are impacted by these events.

<sup>&</sup>lt;sup>22</sup> Rose wrote her first testimony and read it aloud to record it. From then on, her and the other participants' recordings were unscripted.

Minutes later in the same recording, Carina describes how at 35 or 36 weeks pregnant, her midwife discovered that Carina's baby was head up in the womb in breech position. She recalls going for an ultrasound in the same hospital where Michael was taken after his overdose and ultimately died. She explains that the ultrasound machine was not working properly, so she had the procedure in an urgent-care room in the same wing where Michael had been. In her testimony, Carina describes her thoughts in that moment:

The lights are the same. The smell is the same. The colours are the same. She asked me to climb onto the bed and lie down. And suddenly, I'm lying in the same position that Michael was in when I first saw him. The lights are really bright. The smell is really strong. And I realized when I was lying there he never even saw the lights or smelled the smells and he never would, just like he would never see daylight or his kids or even he would never know that the baby was breech. (Dec. 23, 2017)

I was struck by Carina's willingness and courage to speak openly about her pregnancy and contrast her experience of getting an ultrasound with witnessing Michael in his final moments at the hospital. Journalism organizations rarely if ever focus on women who are left to deliver children whose fathers have died from drug-related overdoses, let alone how people manage with the responsibilities of parenting in the aftermath of a partner's death. These are important issues that decision makers and publics need to be aware of in order to understand the ramifications of the crisis.

In a previous recording that Carina called *Papa, No Die* (Dec. 23, 2017), she describes how her children are starting to come to terms with Michael's passing. She explains that one of her children came up with the phrase, "Papa, ouchy," as if to imply that he knew Michael had been hurt in some way. The child then added: "Papa, up," suggesting that that he thought Michael would get better and come home. In the recording, Carina explains how she told him the truth. "No," she said. "Papa not up." A few months later, as Carina explains, her son had begun saying, "Papa, no die. No die, Papa. Papa work." I hear these words as a child's refusal to believe the reality of his father's death. Carina explains that her oldest child says matter-of-factly to the younger one: "No. Papa died." Hearing Carina describe her children's language as they process their father's passing is devastating. I think details like this, as difficult as they must have been for Carina to communicate and may be for publics to hear, are vital in order to help citizens and decision makers recognize the impacts of this crisis. The fact that Carina and Michael's three children have to grow up without their father when Michael's death could have potentially been prevented if more harm reduction services had been available to him is a reflection of the urgent need for authorities to respond more comprehensively to the situation.

As months passed and our work together on the project continued, Carina reflected on the early parts of her relationship with Michael. I believe that her memories of some of her first moments getting to know Michael, and of his personal qualities that helped her fall in love with him, will allow listeners to hear what it means to lose someone you care deeply about. Carina's testimonies are strikingly different than the way media organizations primarily frame drug-related deaths. They rarely provide space for reporting on the long-term impacts of these tragic and personal situations.

In a recording that she titled *Beautiful Nightmare* (Jan. 25, 2018), Carina recalls her second date with Michael and the moment she knew their relationship was going to intensify. She describes how Michael took time to notice and appreciate fine details. She clearly also has an eye for detail, and this comes through in her recordings. Things that might appear inconsequential to others seem worthy of her attention. In listening to Carina's recordings, I sense a connection between her testimonies and her meditation and mindfulness practice. I see a parallel between the content of her recordings and the following quote from the thirteenth century Japanese Zen master Dogen: "Enlightenment is intimacy with all things" (Gregory & Mrozik, 2008, p. 7). The essence of this influential Buddhism teacher's words, and how she and Michael incorporated these teachings into their lives, are reflected in how Carina recalls walking with Michael at Toronto's Leslie Spit Beach on their second date:

I remember sitting in this tree together and watching the weather, taking in this scene of the snow falling really, really, slowly and gusts of wind coming, and at one point a bunch of seagulls trying to fly away from the beach, but the wind was so strong they were just hovering over the shore. And at that moment, I looked over to Michael and I could see his eyelids were covered with snowflakes and his beard was covered in snowflakes. And I had this thought, 'Oh my god, are we going to do this, get to know each other and have a relationship.' You know, enter into that abyss together. (Jan. 25, 2018)

The first apartment that Carina and Michael shared was a former piano factory in Toronto's Bellwoods neighbourhood. It was an open space, except for its sole bedroom and bathroom, and it had tall ceilings and large windows. Aside from being their home, it also functioned as the Centre of Gravity, where dozens of meditators regularly gathered under Michael's instruction. The loft was sparsely furnished, and Carina recalls how she and Michael took great care choosing household objects, such as a Japanese tea cup from a nearby store. She remembers: "Everything that he picked was as if he was curating his space with everything he would need for it. Even if it was functional, it was always aesthetic, and that's something that I really noticed in him as really unique and beautiful. . . . It's something we did together—making home together, making family. It became our art. It was a creative process" (Jan. 25, 2018).

Dominant media organizations rarely portray individuals who use drugs and individuals who experience opioid overdoses as grievable people who cared about their lives and the people they were close to. Publics and decision makers must understand that those who are lost to causes related to drug consumption play significant and vital roles in people's lives, and that their deaths will be felt for a very long time.

Carina also reflects on the moments that imagines immediately preceded Michael's death. She contrasts these with the way she remembers him being so attentive to detail in their early relationship. Carina explains that the fact that Michael overdosed in his vehicle parked next to the library in Victoria seems strange to her:

Michael was really attuned to beauty and detail and ritual. And his death is something that seems so out of character. It's just this moment in time that he was parked downtown in Victoria and took this drug, and then it had the effect it did, and there he is in his vehicle outside the library in Victoria. On this side street next to a big old brick building. Just for this place for him to have this moment, just that it's so mundane. He was so careful with detail and it would have made sense if he'd been parked at a beach somewhere. There's just this out of character scene in the place where he was found. It doesn't match. It makes me feel a sense of desperation in him at that moment. (Jan. 25, 2018)

Carina's testimony resists the assumptions and prejudices that dominant journalism organizations routinely disseminate about individuals who experience opioid overdoses. Michael

was clearly mindful about virtually every facet of life and every action he took. It needs to be understood that the suffering he experienced as a result of his mental illness likely led him to consume a substance that led to his death.

Carina reflects further on what may have prompted Michael to use drugs in that perilous moment. She considers this with compassion, because she recognizes that he was likely struggling with the symptoms of bipolar disorder. She also wishes that some form of support could have been offered to Michael at that critical instance in order to save his life:

If he could have pictured forward in time to now—to our family, the baby—I don't think he would have tried the drug. I don't think he would have done it. I don't think he could have in that moment seen into the future. I've heard from others who have described the experience of a manic episode as if there is not sense of the future and no sense of continuity with the past. It's just the moment and that moment is heavy and expansive and intense and untethered to a regular sense of self. And when I imagine him in that place, I'm just sad that he was alone for that. I can't help but imagine what kind of little ritual he might have done right before he took the drug of what went through his mind, if he was completely controlled by his longing or if there was enough time for some reflection. (Jan. 25, 2018)

Carina's words signal that decision makers must do more to ensure that vulnerable people like Michael do not have to experience a similar fate. In my email responses to Carina regarding these recordings, my aim was above all to acknowledge what I had heard her communicate and offer my support. As far as the contents of her testimony, there was nothing for me to change. My role was simply to be a witness. Everything that she shared was exactly as it had to be. In one particular email, I wrote:

I hear you reflecting on Michael's bipolar disorder with empathy and understanding. I think those are rare qualities, and that the illness is not well understood by so many. I think when the time is right for people to hear your story, they may benefit from the compassion, empathy and understanding you bring to this part of Michael's life. (Jan. 27, 2018) Carina indicated that her recordings felt more "intimate" (personal communication, April 12, 2018) to her than mainstream media narratives. She claimed this was because she felt as though she had told her stories to a close friend, and the fact that she made most of her recordings in her bedroom after her children had fallen asleep. She added that most of the news stories about Michael's death had been "sensational" in her view, and "cherry-picked versions that could be easily digested" (personal communication, April 12, 2018). She told me these media narratives "reduced him to a story that missed his life completely" (personal communication, April 12, 2018). On a previous occasion, Carina indicated that the project felt like an "art project" that she was "doing with Michael" (personal communication, April 2, 2018). "[It is] like a final way to be creative together," she said. Carina indicated that creating and sharing her testimonies allowed her to reinforce her sense of resilience and create further agency. She stated: "I do think vocalizing what's happening is a product of and something that builds more strength" (personal communication, April 2, 2018). In her comments, Carina did not specifically address whether she thought her testimonies could help shift public and policy makers' attitudes and contribute to change.

#### *Rose's recordings as counter-narratives*

Michael's web of connection extended beyond his family and complicates images of lonely bodies in needle-strewn alleys. In our Skype conversations, Rose spoke of a number of themes connected to Michael's passing, of her memories and connection to him, and of her considerable grief. As noted previously, Rose approached the project with a willingness to share a lot about herself, and she never hesitated to speak about the emotional challenges she was facing related to Michael's death. Witnessing Rose move through her grief over the course of several months revealed to me the significance of her relationship with Michael, and how she much she respected and cared about him as a meditation teacher and friend.

Rose wrote and recorded a detailed piece about the first time she met Michael at the Centre of Gravity, and how over time, she came to view him as her meditation teacher. She said at first she was not sure that the centre was the right fit for her, but a particular Buddhist chant that Michael often led touched and inspired her to keep returning. The call and response chant emphasizes that life passes quickly, that it is important to live consciously, and it is a wish for all people to be safe and free from suffering. In her recording, Rose recalls a moment when Michael asked her to lead the chant. She says in that moment, Michael was taking more time than usual to ground himself. In hindsight, I wish I had asked why she had said that. What did she think Michael may have been going through at the time? Did she think symptoms of his mental illness were making it challenging for him to be present?

In her recording, Rose recalls Michael asking her to lead the chant. "I said yes, and he said, 'Do you know it by heart?' And I nodded again. I knew he wasn't asking, 'Do you have this memorized?' but, 'Does your heart know it? 'How are you living it? Are you awake right now?'" (Dec. 20, 2017). To me, this exchange reveals a few important things: the possibility that Michael was suffering in ways that he never articulated to Rose and his other students; that he trusted Rose and saw her potential as a meditator, facilitator, and teacher, and above all as a person; and lastly, Rose's admiration for Michael and her devotion to meditation practice.

For the previous eight years, Rose had attended residential meditation retreats that Michael had led in Ontario and New York State over the New Year holiday. On these five-day retreats, Michael had often asked her to assist with the teaching, and the events were an important part of her life. She looked forward to that time of year, but following Michael's death, the annual retreat could not take place. Rose experienced intense grief and was unsure of how she would spend the holiday. She decided to go to a friend's New Year's party where she danced and stayed up late. The party could not have been a greater contrast to the quiet and seclusion of the meditation retreats she was accustomed to attending. In spite of the differences, Rose tried to adapt as best as she could, but she says she found it difficult. In our conversation, she recalled an instance when she was dancing at the party.

There was a moment that I was like, my friends had a party, and there was a dance floor and a DJ, there was a moment when I was looking at the floor, and I was having a good time, and then all of a sudden, I was just struck, like, 'Oh, Michael's dead. He's not here to celebrate this new year.' I just stopped and had a moment, and was aware that I was having an experience that was tender. I couldn't let myself stay there, because it was almost too much. It was almost too intense. It was like, 'Now you're here, so you have to experience here.' But I honoured that this happened, and it's strange how I'm in the world and he's not. (Jan. 7, 2018)

In a later conversation, Rose remembered how on New Year's Day, she continued to feel Michael's absence and tried to cope with the situation. After the retreats with Michael each year, they ate together at the same Italian restaurant in Toronto's west end. Just as much as the retreats, the meal had become a tradition that she cherished. In our discussion, Rose described planning to go to the restaurant on January 1<sup>st</sup> with a friend, but the friend called to tell her the restaurant was closed.

I said, 'I just passed by there last week. There's no way it can be closed.' She said, 'You know, it's boarded up, so we can't go to that restaurant.' And I was really upset at first. This was my plan. 'How am I supposed to do the thing that reminds me of Michael?' This is a tradition that I wanted to keep, and pretty much right away, I thought, oh, this is Michael's way of saying, 'Don't hold on. You can remember me, but you don't have to be in the same spot. It doesn't have to be so rigid. Could you just have pizza...Thinking about the tradition is nice, but it's not necessary to remember me like that. Let it go. Don't hold on.' (Jan. 21, 2018)

As I listen to Rose's recording from our conversation, I am mindful that not everyone who hears her testimony will have had a personal connection with a meditation or a spiritual teacher, let alone with Michael specifically. Part of me wanted to ask her to explain what role he filled in her, but I recognized that her self-reflection and vivid descriptions will communicate these points. I am reminded that it is much more effective for writers to 'show' instead of 'tell,' and Rose succeeds in doing this in her recordings. What stands out above all to me in her memories about her first New Year holiday following Michael's death is her longing for him to be there, and for her to be able to relive the things she was accustomed to doing together. These memories communicate that although people who die of drug-related deaths are often presented as social outcasts and who are undeserving of harm reduction services and health care, each death has deep and lasting repercussions for decedents' loved ones. Countless people across North America are facing the daunting challenge of spending holidays and marking significant moments without their loved ones who have died from preventable overdoses, yet we rarely learn about this in dominant media discourse.

In another of our exchanges, Rose (March 11, 2018) shared how she was feeling overwhelmed with the deep grief she had been experiencing. She said she yearned for a break from it. Although it was clearly challenging for her, I saw that Rose seemed to accept it as part of her process. I did not pressure her to speak about anything that might upset her further or to try to change the way she was feeling. On that day and at other times, my aim was to allow for a lot of space in our conversations in order for us to be with what was. I made simple gestures such as nodding my head, and said that I understood and could see how difficult it was for her. The fact that we had months to record Rose's testimonies, combined with her wholehearted commitment to the project, allowed us to never feel rushed. There was a natural and relaxed pace to our discussions. I think this allowed Rose to share details about her inner life and communicate things that are rarely presented by media organizations about the impacts of drug-related overdoses for people who are closely connected to those who have died.

Rose indicated that she believed her testimonies contrasted with dominant narratives, because she said journalism organizations often represent individuals who experience overdoses in stereotypical ways. She stated they are regularly "seen as less than or as people who aren't contributing to society in some way, that their addiction is somehow their own fault and not the responsibility of all of us to figure out what is happening and how we can respond to this epidemic" (personal communication, June 2, 2018). Rose added that Michael risked becoming "another statistic," and as a result, she had felt motivated to tell the "background" of his story (personal communication, June 2, 2018). She claimed that doing so enabled her narratives to be unique. She stated: "We're not talking about this death very much. We're talking more about the impact he had on people. I feel more connected to 'this is the influence he had on my life…and he is gone,' but I'm not so fixated on how he went" (personal communication, June 2, 2018).

By reflecting on Rose's responses, I was reminded of one of her recordings in which she examined the intimate nature of her friendship and student-teacher connection with Michael.

Through my relationship with Michael, I learned how to explore and engage with my life in deeper ways. To investigate how thoughts, actions and words matter. How we show up or shut down matters. To recognize when we are caught and explore that together. That we could do this together in our relationship when difficult things came up between us was so healing, for both of us. . . . Michael always encouraged me to develop greater awareness to the natural world, that nature was the best teacher, and how we were not separate

from nature itself. I could feel this connection growing when he was still alive and I feel it now, even after his death. . . . My hope is that the listener understands the impact Michael made on my life. (Jan. 7, 2018)

In a later recording, Rose pointed to the manner in which journalism organizations often report on people's overdoses, particularly those of well-known individuals. She added that they rarely investigate in substantive ways how these deaths impact decedents' loved ones over time. She said: "No one is asking, 'What is life like for them now that their husband, father, friend, lover, brother, sister, etc. is gone" (March 11, 2018).

Rose's visceral descriptions of her grieving process reveal Michael's passing has impacted her in profound and sustained ways. She explained:

Grief is not a linear process. It comes in continuous waves. Builds. Crests. Falls. Recedes. Repeats. And it can often overwhelm me. . . . For me, the experience of losing Michael still feels like a shock in my body, but I don't feel paralyzed by fear. I no longer wake up in night sweats. My capacity to hold his death is widening, but the depth of it still cuts deep. And that anger is part of the grieving process, even though that doesn't feel appropriate, because it doesn't change the fact that he is gone. Recognizing when my ability to hold my grief feels destabilizing and what I need to do be a functioning human. Grief is touch and go sometimes. Sometimes you can touch it and sometimes you can't. Grief never ends, it just changes and takes different forms over time. But I don't think I'll ever "get over" this loss. (March 11, 2018)

### Andréa's recordings as counter-narratives

In her first recording, Andréa discussed how Michael gently encouraged her in her meditation practice. She recalled how he had told her that he timed the length of his own meditation sessions by lighting green incense sticks that took half-an-hour to burn. She described watching incense and reflected on impermanence, one of the core teachings of Buddhism: "The smoke was coming out of it and creating the most beautiful, evolving, and expanding shapes that reminded me of the incense being us and our lives being the part that is burning and then becoming both smoke and ash" (Dec. 15, 2017). Andréa also remembered attending Michael's

memorial service and holding his ashes. She stated: "[I was] feeling so surprised and astonished that a whole life could become ashes and the whole body could fit inside a vessel, and that magic of transformation and the sadness of that transformation from being a big, live, warm body to a cold body and into an ash body" (Dec. 15, 2017).

Andréa's recording illustrates the feelings that many people have in the wake of the death of someone who is close to them. People often struggle to understand how their loved ones were present and are now gone. I think it is vital that publics and policy makers learn more about how fatal overdoses lead bereaved people to go through similar processes. We need to know that individuals who die from drug-related overdoses are grievable. Unless there are more nuanced narratives in the media about how fatal drug-related overdoses are felt by decedents' families, friends, and communities, the notion that these deaths are unimportant risks being perpetuated even further.<sup>23</sup>

Andréa recalled being present for the birth of Carina and Michael's first two children. Like Rose, she travelled to B.C. nearly six months after Michael's death to offer her support to Carina when she gave birth to her third child. After a week with Carina, the baby had not yet arrived, so Andréa extended her trip and was able to be there for the delivery. It was important for Andréa to be present in order to assist Carina, whose experience was obviously affected by Michael's passing. In the midst of all the activity around the birth, Andréa woke up early in the mornings and found time to make a couple of recordings while walking outdoors. I appreciate the effort she made to chronicle her experiences, even though I am sure she could have used the rest. In one recording, Andréa talked about how Michael's death became vivid for her as she spent time in the house he lived in with his family. Although it was understandably challenging for her, she focused on her feelings of gratitude for being able to support Carina and her admiration for her friend. She says:

It's been amazing to see a friend grieve the passing of her love with such skillfulness and really seeing the practice of meditation and the teachings of the Buddha alive and as this brilliant example of being in the moment of being really sad and then being happy and making jokes and worry about different parts of the future and also trusting what's happening and just managing with

<sup>&</sup>lt;sup>23</sup> In a rare example of long-term reporting on the impacts of the opioid crisis, journalists with *The Toronto Star* (Mathieu, 2018) spent a year documenting how the family of 22 year-old Justin Lidstone, who died of drug-related overdose in October 217, has been affected by his passing.

perseverance and love and tenderness and feeling overwhelmed but then also feeling so grateful for all the help that's coming even though it never even comes close to replacing Michael in his immense capacity to get things done and get food on the table and fix things and play with the kids and be tender to Carina. None of us can ever replace that and so we do with just little bits of support for her in our own ways. (Dec. 26, 2017)

Andréa's recording reflects her personal strength in the aftermath of deep loss. Dominant media narratives rarely give space for this type of information. Although families and friends of individuals who experience fatal overdoses are affected in many ways, we need to know that they are often determined to carry on and to support others. One of the ways that Andréa transforms her grief into positive action is by committing to helping Carina and Michael's children. She reflects on how she hopes to keep Michael's memory alive for his children as they grow older without their father.

I always wonder what it meant to be a good godmother and how I can be present in their lives, even though I live 5,000 km away. It's an ongoing question that I ask myself and I see that right now being a good godmother is being present with their mother. . . And also thinking of ways of encapsulating Michael's essence and stories, so one idea that I have is that I want to ask 10 close friends to write short letters to the boys about their dad and little details they remember about him and moments that they lived with him and their impressions of who Michael was and the different ways that Michael was and lived and the different things he did. (Dec. 15, 2017)

Andréa explored how she initially found it difficult to accept Michael's passing and the way that he died. She said mindfulness and the teachings she learned from Michael helped her come to terms with it. Yet, like Carina, she explained that she sometimes thought about his last moments and what he may have been thinking. She stated: "I can feel my mind how it wants to know what happened, and what led him to make those choices, and how much was it the illness, and what was the illness doing in his mind and his heart, but coming back to just agreeing to not know and accepting not knowing feels like a place of rest" (Dec. 26, 2018).

The purpose of the project is to humanize Michael, but not to idolize him. My collaborators do not see Michael as a flawless person and did not attempt to represent him this way. His death and her grief prompt Andréa to remember times when as a meditation student, she had opportunities to see Michael as a "super stable, grounded leader and teacher" (Dec. 26, 2018). She also recalls moments when her friendship with Carina and Michael allowed her to see Michael as "tired and frustrated" at home, "overwhelmed by household stuff and kids," and "in dark moods" (Dec. 26, 2018). She describes the "intensity" (Dec. 26, 2018) of those moments, and how Carina tried to support Michael. With care and compassion, Andréa expresses her admiration for Michael for how he tried to manage his condition for years. Many reporters indicated that Michael had suffered from bipolar disorder in their articles about his death. Yet, media organizations need to look beneath the surface more often when it comes to their coverage of the opioid crisis and overdoses. If journalists were to more frequently draw connections between issues including mental illness, the lack of harm reduction services for vulnerable people, and the spiraling rate of overdose deaths, they could help disseminate helpful information about the crisis.

In her responses to her recordings, Andréa also noted that her testimonies disrupted dominant narratives, because there are few media stories about people involved with yoga and meditation who have experienced fatal overdoses. She added through her recordings, she was "humanizing Michael as a father, as a teacher, as a partner, as the responsible loving being that he was" (personal communication, June 6, 2018). She pointed to specific details in her testimonies that helped illustrate who Michael was. These included how Michael was present for the birth of his first two children, how Carina supported him when he struggled with his mental illness, and how his condition likely contributed to his death. Andréa also stated that by speaking about the communities Michael built, his "unfinished projects," and how Carina "manage[d]" in the aftermath of his death, helps to create new knowledge about Michael and individuals who experience opioid overdoses (personal communication, June 6, 2018).

### Test listeners' responses about recordings as counter-narratives

As noted previously, my collaborators expressed interest in sharing their recordings with a small group of people in order to learn how their testimonies were received and understood before we published them online as part of the memorial. The participants identified five individuals who were friends of Michael's. I emailed them and invited them to listen to some of the recordings, respond to a few questions, and share their feedback with my collaborators and me by email. Three individuals responded, although the information that I received from one person lacked clarity and focus, and I was unable to use it in this thesis.

At the time that I shared the participants' recordings with the test listeners, we had not yet completed the digital memorial, so they only commented on the audio recordings. I asked these individuals to consider whether they thought that Carina, Rose, and Andréa had resisted dominant media narratives about the opioid crisis and people who experience drug-related overdoses by creating and sharing their testimonies. In what follows, I share some of the details of their responses to the recordings.

## Erin Robinsong on recordings as counter-narratives

Erin Robinsong is a poet and facilitator based in Montreal. She was a friend of Michael's and edited many of his writing projects. She was also a part of the Centre of Gravity for many years and is friends with Carina, Rose, and Andréa. She wrote that listening to the participants' recordings allowed her to see grief as a "love relationship" that can be felt and expressed in countless ways (personal communication, Aug. 11, 2018). Erin stated that particular details in the participants' recordings helped her gain a vivid sense of the impact of his death. These moments included Rose speaking about missing Michael at a New Year's party, and Andréa describing what would have been Michael's last sunrise and sunset. She also referred how Carina recalls moments in her early relationship with Michael, the green couch they shared, the Japanese pottery they picked out together, and "seeing snow stick to his beard as they watched seagulls flying against the wind" (personal communication, Aug. 11, 2018). Erin claimed:

These recordings brought me into those details, grounded me in his death in a daily relationship with it. . . . One of the most painful gifts of death seems to be that we notice all the details —perhaps like when we first fall in love, seeing and remembering everything so vividly. (Personal communication, Aug. 11, 2018).

Erin indicated that "mainstream journalism coverage" of the opioid crisis and Michael's overdose in particular felt too simple and overly focused on the "shocking" fact that a meditation teacher had died of an overdose (personal communication, Aug. 11, 2018). She added that my interlocutors help to humanize Michael by telling stories and sharing memories in which he

comes across as a complex person. She explained: "In them we see his vulnerabilities, his struggles, his strength, his wisdom, his beauty, his complexity, the depth of his relationships" (personal communication, Aug. 11, 2018).

Erin's feedback confirmed my feelings about what makes my collaborators' testimonies unique and allows them to challenge dominant narratives about the opioid crisis. Denigrating images of people who experience fatal overdoses cannot begin to communicate how these deaths impact decedents' loved ones. As Erin indicates, these losses are felt in profound and complicated ways. The details that my collaborators share about their memories and grief highlight how they experience Michael's death in critical ways.

## Katherine Kline on recordings as counter-narratives

Katherine Kline is a psychoanalytic psychotherapist and a friend of Carina's who also knew Michael. She described listening to the participants' recordings around the anniversary of Michael's death. She recalled that following Michael's passing, she received a number of interview requests from journalists. Echoing Erin, she noted: "There was a tendency to emphasize the drama of a fallen guru" (personal communication, July 29, 2018). She indicated that some reporters seemed to prioritize Michael's "good looks," and that she kept trying to draw the conversations back to issues of mental and emotional health. Katherine said that she considered how very few people who lose loved to overdoses are ever invited by the media to tell their stories. She argued that it was only because Michael was a public figure that his death was deemed important to cover.

Katherine took considerable time to respond to my queries and indicated that she listened closely to the participants' recordings and felt very moved by them. She said that she hopes the "intensely personal nature" of the testimonies will lead people to empathize with my interlocutors and Michael (personal communication, July 29, 2018). She claimed that "[1]istening felt like mourning with" (personal communication, July 29, 2018). She also insisted that more discussions about the role of mental and emotional health in the media could help create a greater understanding about the crisis and vulnerable people. Katherine indicated that she felt Andréa contributes to this by recalling how she witnessed Michael in distress.. She added: "Michael's struggle is very relatable. Who doesn't want to feel soothed and sedated at times? Who doesn't want relief from their own inner life?" (personal communication, July 29, 2018).

I appreciate Katherine's insights, which also help to humanize Michael and others who use drugs and have experienced overdoses. I concur that by speaking openly about Michael's mental illness, my interlocutors may help others who engage with the project understand a deeper layer of his story. The challenges that many people who use substances often face are not always visible. It is also disappointing but not altogether surprising to hear Katherine's perspective about how media organizations responded to Michael's death by accentuating his physical attributes and sensationalizing his passing. I agree with Katherine that it is unfortunate that very few people whose family members and friends die from drug use have opportunities to share their experiences through the media. Further in-depth narratives created by individuals who are impacted by the crisis could help challenge stigma and prejudice about people who use drugs and experience overdoses.

### Crafting grief and continuing bonds theory

Rather than viewing grief as something that bereaved people must endure, this project provides opportunities for its participants to engage with their pain in agentic, creative, and aesthetic ways. In producing their narratives about Michael, my collaborators remember him as more than someone who died from an opioid overdose, and they communicate how his life and passing personally impacted them. In doing so, they resist Kübler-Ross's (2016) widely accepted model, which suggests that people who are grieving or have terminal illnesses experience five distinct and chronological phases that ultimately end with acceptance, as outlined in Chapter 1.

In contrast to Kübler-Ross's (2016) paradigm, *The Crafting of Grief* (2016) by Hedtke and Winslade articulates a method for how bereaved or dying people can tell their stories using the narrative approach. The practice is meant to support people as they face suffering and grief and help them identify instances of "beauty among moments of pain and loss" (Hedtke & Winslade). Hedtke and Winslade write that crafting grief is not only suitable for therapists, but also for others who assist people who are grieving or facing terminal illnesses, including medical professionals, social workers, relatives, friends, and I would add researchers and even journalists and documentary makers. Hedtke and Winslade claim that rather than trying to match one's individual experiences with a prescriptive model of grief, crafting grief allows people to navigate their own paths and express themselves in creative ways. They build upon Hilde Lindemann Nelson's understanding of narrative in the sense that people react to death and dying by weaving their experiences "into the plot of a grief narrative" (2001). The authors also draw from Deleuze (1993), who, in their words, compares the process of building a narrative to "sewing a hem: folding, twisting, and pinning it along a line" (Hedtke and Winslade, 2016). Hedtke and Winslade add: "The line is the narrative plot. We fold experience back on itself, each time we do so, add a layer of depth to it by retelling, in addition to performing it in action" (2016). By sharing memories about Michael and exploring their feelings in the aftermath of his death, my collaborators often recall precise moments in detailed and unique ways. For instance, by examining how she spent the first New Year holiday without Michael, Rose crafts a compelling narrative, and in doing so produces original and nuanced knowledge.

Crafting also implies that people who are experiencing the loss of a loved one or are facing their own death have choices and that there is not a single way to experience grief. Hedtke and Winslade (2016) insist it is vital that people be reflexive and observe how the process of crafting grief changes them. They add that the term also suggests that special skills are not required, and that anyone can take part in it the process if they choose. Although crafting can involve elements of science, it is also artistic and aesthetic work. Hedtke and Winslade build upon how Judith Butler (2013) uses the word "crafting" in her dialogue with Athena Athanasiou. Butler makes a Foucauldian argument that it can allow people to individually express themselves, in spite of pressures to conform to wider society. In doing so, Hedtke and Winslade claim that people act in empowered ways and challenge "regimes of truth" (Foucault, 1980, p 133) and hegemonic narratives about grief and dying. They argue that crafting enables people to resist traditional grief psychology models such as Kubler-Ross' (2016), which claim that it is beneficial for people who are grieving to consider that the connections they had with people who have died are over, and to begin new phases of their lives without the deceased. Hedtke and Winslade insist this forceful separation is unnecessary and can cause people to needlessly suffer.

Using language from Hedtke and Winslade, my interlocutors "design" their grief and their "own experience[s] like a work of art" (2016). In doing so, my collaborators simultaneously disrupt how stories about people who experience fatal overdoses are frequently communicated in the media, and the manner in which their loved ones are often silenced. I consider the participants minoritized subjects whose experiences and voices are not normally heard or deemed legitimate. In sharing their private memories and expressing their pain with the public, my collaborators reconceptualize grief as it relates to the overdose crisis as collective, ongoing, creative, unpredictable, and social. In crafting their grief, the participants are taking up positions of agency. Exploring and documenting their experiences also leads them to change, and as Hedtke and Winslade write, they "become different people as a result of the process" (2016).

I considered how I could invite my collaborators to experiment with the narrative approach. According to Hedtke and Winslade (2016), it can be helpful for people to ask respondents questions in ways that encourage them to be self-reflexive and agentic about their unique experiences, rather than suggesting calculated or scripted ways of grieving. They claim this can help support people in viewing their grief and narrative process as a creative endeavour, and not as something arduous that they must go through. They recommend that those asking questions touch on themes that respondents raise in the context of discussions and ask them to explore these in greater depth. They indicate there is no limit to the types of questions that one can ask, but they emphasize that the benefit of inviting people to speak is that they feel empowered and connected to individuals who have died. They assert that questions can be developed with the intention of seeking respondents' individual insights as opposed to trying to validate accepted norms, particularly those about grief.

In their recordings, during our Skype conversations, and in their emails, the participants revealed how they were crafting their grief. They often spoke about moments when they continued to feel Michael's presence and engaged with him in their day-to-day lives. My collaborators indicated to me that they were not interested in getting over Michael's death or moving on from it, as Kübler-Ross (1969) encourages bereaved people to do. In this section, I highlight my attempts, inspired by Hedtke's work on continuing bonds theory, to assist my collaborators in examining how Michael remained in their lives. Hedtke believes that people who are grieving can find ways of incorporating the "stories, meanings, and values" (2012, p. 12) of deceased loved ones into their ongoing lives. She draws inspiration for writing about the ongoing bond theory from Barbara Myerhoff (1978), who taped testimonies of residents of a retirement home in California, and from Michael White and David Epston, who incorporated Myerhoff's concepts in their work as therapists. Hedtke maintains that people can deliberately invite respondents to explore ongoing bonds with decedents, as opposed to focusing on the fact that those who have passed away will not return (2012, p. 82-83). She suggests that it can be helpful to pose questions that encourage people who are grieving to reflect on deceased people's strengths, including how they experienced difficulties related to their deaths, and their most impressive actions in life before they passed away. Hedtke adds it can also be beneficial to ask

respondents how they view their own resilience, and which qualities of those who have died they may want to preserve.

She contends that it can also be beneficial to invite people to reflect on what their loved ones who have passed might say to them in the present (2012, p. 93). This is not meant to engage people who are grieving in unrealistic or even unethical practices. The purpose is to assist respondents in developing ongoing bonds with their loved ones. In order to encourage people to identify decedents' voices, Hedtke recommends questioners use subjunctive as opposed to indicative verbs (2012, p. 95). She insists that this can allow people to reflect on what could be imaginable and not the mere facts of their loved ones' deaths. Accordingly, I asked my collaborators subjunctive questions in order to invite them to speak about their ongoing bonds with Michael. My questions included: 'What do you think Michael would say if he were here?'; 'How do you think Michael might respond'; and, 'How do you think Michael would feel about this?' According to Hedtke, questions such as these can be healing, and help people following the death of a loved one develop a feeling that an individual who has passed away remains close to them (2012, p. 97). In what follows, I share highlights of my interlocutors' reflections on how they engaged with continuing bonds theory in the project.

# Carina: Continuing bonds

In a recording and without me prompting her, Carina (Feb. 14, 2018) reflected on ways that she continued to feel Michael's presence. She remembered how she wore Michael's clothes throughout her pregnancy. She also discussed how her new baby looked a lot like Michael, not so much as he did when he was young, but as an adult. She spoke about intricate drawings that Michael made for his children that remained taped to their refrigerator, and how they were a constant reminder of him for their family.

In an email (personal communication, April 11, 2018) that I sent to Carina, I asked if she felt her process of creating her recordings was allowing her to sustain a connection with Michael. She responded that in the first months of the project, her memories and testimonies focused mostly on positive elements of their relationship, and that she was constructing an "idealized" version of him (personal communication, April 12, 2018). She said this allowed her to feel close to Michael. However, she added that she had begun processing "more of the shadows" of his personality and their relationship (personal communication, April 12, 2018). She indicated that she was doing so with a feeling of greater distance between them.

I initially hesitated, but I asked Carina to imagine Michael being present, observing her daily life, and speaking to her. I worked with the discomfort, recognizing that if Carina was willing to consider such questions and respond to them, it could potentially enrich her testimonies and benefit her and others. In my email (personal communication, April 11, 2018), I asked: "If Michael were here or looking at you in your day-to-day life, what thoughts do you think he might have? What do you think he might say if he could speak to you?" Carina seemed to welcome the questions and responded thoughtfully as she always did.

I think, right now, he'd be concerned. He'd ask me what I need to do to take care of myself. A lot of my energy is going out into the world. The kids need me close. He'd encourage me to get focused on immediate needs, including self-care. He'd also be sad. He'd apologize, he'd tell me he loves me and that he wishes he could comfort me. He'd tell me the way forward will be easier than I think. (Personal communication, April 12, 2018.)

By speaking with Michael in the present moment, Carina helped to underscore how intensively she was experiencing his loss. Her words also countered dominant media narratives that suggest that people who use drugs and experience fatal overdoses are not grievable or worthy of being remembered. Carina will clearly continue to bear the burden of Michael's death and he will remain in her heart and mind for a long time.

### **Rose:** Continuing bonds

I also felt somewhat apprehensive about asking Rose to explore speaking with Michael in the present moment. Yet, I sensed the level of trust between us had grown sufficiently, and that inviting her to do so might allow her to reveal insights about her experiences of grief for herself and people who engage with the digital memorial. Michael's voice came quickly to Rose, and she shared what she thought he might tell her. Her words reflected the closeness they shared, the way she felt supported by him, and how he helped her feel more self-assured. Rose stated Michael would say:

You don't have to hold that all on your own. Whatever your thinking is, let's talk about it. To hold that by yourself only makes that energy bigger, more

forceful, but if you let someone share that responsibility, then you don't have to hold it on your own. It won't create stronger and stronger grooves. (Personal communication, Feb. 11, 2018)

Hearing Rose convey the words that she believed Michael might say gave me a vivid sense of who he was and still is for her. It is one thing for someone to say, 'I am deeply grieving,' or to read about people who have lost loved ones to overdoses in the media. It is entirely different to have an opportunity, as I did found in this dialogue with Rose, to witness her engage in conversation with Michael in the present moment. Her words reflected the depth of her grief and how Michael remained an important person to her, even though he was not physically present. The vibrancy of our exchange, I believe, led Rose to share more details with me. I asked if she had more questions she would ask Michael if he were still alive. She said: "Where are you? His physical form is gone, but I still feel him. I wonder what form he is in. I wonder if he can feel the people around him, if he still has a relationship with the material world of the universe. Where do you go? What's it like?" (personal communication, Feb. 11, 2018).

I also invited Rose to speak with Michael in the present moment in order see if she would be willing to explore more of her feelings about his passing. Rose told me that she felt a considerable amount of numbness and anger about the "risks" Michael took by choosing to use street drugs that led to his death (personal communication, Feb. 11, 2018). At the same time, she said she recognized that he "wasn't in his right frame of mind" or in "a stable state" (personal communication, Feb. 11, 2018). Yet, she wondered out loud how, in spite of his suffering, Michael could have risked his life with a young family. She stated: "I can't reconcile that right now, but he was having conflicting thoughts and feelings. I can hold that understanding and yet, I feel angry" (personal communication, Feb. 11, 2018). As though she was addressing Michael directly, Rose questioned what could have prompted him to take such great risks on the last day of his life:

What was going through your mind that day? In the parking lot. In the truck. What were you thinking about? What was so awful? What were you trying to escape from? Why couldn't you have shared that with anyone. Could I have done something? (Personal communication, Feb. 11, 2018) Each question seemed to lead to another for Rose, but she added that rather than helping her find answers, it felt like a "dead end" (personal communication, Feb. 11, 2018). She indicated that she wished she had asked Michael more questions while he was alive.

I asked Rose, "Do you believe your conversations with Michael can continue?" (personal communication, Feb. 11, 2018). She replied that she did, but in that particular moment, she stated that her anger was preventing her from being open to what Michael might have to say, and that it was masking a great deal of sadness. She added that she needed a break from feeling it. "It's too hard," she said. "It's too heartbreaking. And then on the other side, I'm also afraid I'm going to start forgetting things about him. It's been seven months since he passed. I can't believe it's already been seven months. It feels like yesterday and it feels like forever" (personal communication, Feb. 11, 2018).

Although Hedtke (2012) suggests that communicating with individuals who have died in the present moment can have transformative effects for bereaved individuals, Rose's experiences illustrate that it is not always a smooth or easy process. At the same time, the words she shared in this process challenge the way dominant media organizations portray individuals who experience fatal drug overdoses as forgettable. The fact that Rose felt compelled to ask Michael in the present about the circumstances of his death, and wrestled with her mixed emotions, illustrates that his death impacted her in significant ways. The media has largely failed to find effective ways of communicating how individuals often struggle to come to terms with the overdoses of people they care about. The digital memorial that I have created with my collaborators allows them to share how they are attempting to accept Michael's death over a prolonged period.

In the conversations that followed the one that I highlighted above, Rose spoke about her ongoing bonds with Michael, often in beautiful and moving ways. She explained that she first learned about Buddhism from Michael. It was through Michael, she said, that she also connected with a meditation community whose members she grew to care about. She recalled how she felt that Michael recognized her potential and supported her in her growth, not only as a meditator but as a person. She said: "He influenced my life so much. And that doesn't just stop. You just can't cut that off. He gave me so many things" (personal communication, Jan. 7, 2018).

Rose also recalled how Michael once signed off on an email to her. "I will never abandon you," he wrote. "And that still feels true," Rose said (personal communication, Jan. 7, 2018). She told me about other things that Michael might have said if he was still alive, such as, "I'm right here. I haven't gone anywhere. I've given you all the tools to deal with this. You know life is

impermanent" (personal communication, Jan. 7, 2018). Rose added that she often responded by saying to him, "I knew there is impermanence, but I didn't think it would be applicable to you or so suddenly" (personal communication, Jan. 7, 2018).

Rose's conversations with Michael illustrate that although he had died, he remained an influential and positive force in her life. She described how she felt Michael's presence most clearly while she was engaged in physical activity outdoors, even if it happened to be in the middle of the bustling city.

Riding my bike, just the sun reminds me of him. I can feel him in the elements. I could feel him in the crystalized snow, in my body that way as well as in the world outside. I feel his teaching crystalizing inside me. This morning, I went to a yoga class. I can picture his body, what he would say while he is leading a class. Sometimes that is a bit overwhelming to me. I feel him in ways that I'm not even expecting. (Personal communication, Jan. 7, 2018)

Rose is an avid swimmer but explained that she cancelled her membership at the YMCA after Michael died. She recalled how she used to swim before her monthly interviews with Michael, and said she could not bring herself to continue her swimming after he passed away. However, in February, nearly seven months after his death, she said she got back in the pool. She explained that moving her body and doing laps brought Michael's memory back to her in visceral ways.

I was anxious before I went. I was like, 'Am I going to be any good at this? It's been a year. Am I going to be able to swim as well? What's my stroke going to be like?' And I got there and it all came back to me. And more than just the strokes, it was all the feelings that I would have about meeting with Michael and things that I was grappling with. It was like all of these other things came flooding in at the same time, and I had a very strange experience of time in the pool. I was like, 'The last time I was in the pool, Michael was alive, and my body doesn't understand.' In this fluid environment, my body doesn't understand that that's not still true. Or maybe the opposite, like, 'In this pool, Michael is still alive, because there's so much aliveness in this pool of Michael

the last time I was here, and I'm just experiencing that again.' Time is just warped. Time is very strange. I was like, 'He's alive, but he's not, but he is. And this is proof that he is.' (March 11, 2018)

Rose's experience of sensing Michael's presence while swimming is in itself a compelling challenge to dominant media narratives about the opioid crisis and individuals who experience fatal overdoses. Bereaved people often continue to feel close to individuals who have died. The deceased often remain important to grieving people for a long time. Yet, Rose reminded me that feeling the presence of people who have passed away can sometimes feel challenging. After she visited Carina and her family in B.C., Rose recalled seeing Michael's home and the things he left behind. She referred to his shoes, drawings that he made for his children, his handwriting on the refrigerator, his list of projects and flights he was planning to take, and notes about his workout routines in his office. She stated that these objects seemed to heighten the sense of Michael's presence for her. She described the impact as "incredibly overwhelming" (personal communication, Feb. 11, 2018). By being willing to feel Michael and speak with him in the present, Rose was able to communicate the depth of the bond they shared and the lasting impact of his death for her. None of the mainstream media coverage about Michael's passing was able to convey this kind of information.

# Andréa: Continuing bonds

In a phone call with Andréa seven months after Michael's death, I asked if she was interested in exploring continuing bonds theory. She said that she was, but explained that her experience with grief was shifting. Up until that point, she explained she had felt Michael's presence quite closely and consistently. As time passed, though, she said that she felt him growing further from her, and she was beginning to accept what had ultimately happened to him. She added that since the birth of Carina and Michael's baby a month earlier, she sensed Michael's "spirit" was not as accessible to her as it had been following his death (personal communication, Feb. 12, 2018). At that time, she said she spoke with other members of their meditation community and they often cried and supported each other. As the months has passed, she explained that many of these individuals had resumed their busy lives, and she stated she missed the closeness she felt with them. In reflecting further on her experience of Michael's presence, Andréa said: "It's a good thing that he has moved on, doing what he needs to do,

preparing to come back or entering the nothingness – that big mystery—and that adds to the faraway-ness."

In listening to Andréa, I was reminded of my situation vis-à-vis my mother, coming on three years since her death. I do not know exactly when the heaviness of my grief related to her passing lifted, but it must have been roughly two years after her passing. I think I was too busy to know exactly when my feelings shifted, and it was a gradual process, but I can relate to Andréa when she spoke about Michael's presence seeming further away to her. As Hedtke and Winslade (2016) explain, Andréa's testimony indicates that we all experience the deaths of people we are close to in our own ways. There is not a single path of grief. Yet, this does not mean that people who experience fatal overdoses are not grievable, as dominant journalism organizations often suggest.

Before we ended our call, Andréa recalled something that Michael used to say, which is at the heart of Buddhist teachings: "You will die. I will die. Do not resist it. Try to accept it" (personal communication, Feb. 12, 2018). The challenge for her, as she explained it, was that Michael left those who loved him, including Carina, Rose, and her, with a mystery about why he risked his life by consuming street drugs. Andréa referred to how Buddhist teachers in the Zen tradition often present their students with poems, or *koan* in Japanese. These short poems are often not immediately easy to understand, and they require that people reflect on them before deeper meanings often reveal themselves. It is possible that in time, by contemplating Michael's life and a multitude of factors, that my interlocutors may gain insights and greater acceptance of the conditions that led to his passing. I appreciate how difficult this process may be for them, as it would be for anyone who loses a loved one to an overdose.

We can never fully understand the pain that decedents with mental illness like Michael may have faced, but in the aftermath of fatal overdoses, it is critical that journalism organizations avoid stereotyping individuals who die from causes related to drug use and report on these deaths in sensitive ways.

## Becoming

Hedtke and Winslade (2016) suggest that it can be valuable for individuals asking questions to encourage respondents to examine how they are changing or becoming different people in the process of producing their narratives of grief. They suggest that people who are grieving can consider how the passing of loved ones may lead them to evolve, even in minor ways. They contend that in doing so, people may find new and even hopeful or optimistic ideas about continuing to live, even as they navigate their grief.

In April 2018, as our period of recording testimonies neared an end, I asked my collaborators by email if they believed they had changed as a result of taking part in the project, and if so, in what ways. Were they the same person they had been at the time of Michael's death? Had they "become" different people as a result of producing their testimonies and the digital memorial? Did producing their narratives allow them to claim agency and become empowered, particularly in light of the fact that dominant media narratives often denigrate people who experience overdoses and silence their loved ones?

Carina responded and indicated that vocalizing her experiences since Michael's death allowed her to feel stronger. She added that creating her personal narratives and engaging in other activities that were not connected to the project meant she had to focus her energy away from her daily life and children. She indicated that she was beginning to require something different, that her "need for externalizing" had diminished, and that she felt compelled "to fold into [her]self, to cocoon" (personal communication, April 12, 2018).

Rose explained that the process of creating her narratives provided her with opportunities to become more aware of her emotional states, to listen to her inner voice, and to take breaks from the heaviness of grief when she felt it was becoming too much. She added that the project allowed her to recognize the fleeting nature of life and the importance of relationships. She said that it also helped her recognize times when she felt vulnerable, hopeless, and mistrusting of the world, but also moments when she felt bold and empowered. She stated that she sometimes reminded herself of what Michael used to tell her:

'Don't be afraid of your life.' And it makes me feel like I have more control over my life, and that I should jump and leap into things that I might be feel sacred about or timid or shy about. It gives me like a little bit of a push to be like, 'Don't be afraid.' I don't know which of those selves is going to show up – the small one or the one that's ready to jump. And I think Michael was always encouraging me to be the person who jumped. (Personal communication, Jan. 7, 2018) Rose and Carina's reflections on becoming suggest that the process of recording their testimonies and producing the digital memorial allowed them to resist dominant narratives about the opioid crisis and individuals who experience fatal overdoses. Along with Andréa, my collaborators have shattered the silence that is imposed on bereaved people, often as a result of stigmatizing media coverage of people who use drugs and experience overdoses. My interlocutors have communicated openly and courageously about their connections to Michael and their grief. In doing so, they have developed agency and shared knowledge about themselves and Michael.

#### Listening deeply and unpacking the recordings:

#### Participants' insights and my autoethnographic reflections

A month after we published the digital memorial, I invited my interlocutors to have further hour-long, one-on-one conversations with me about the project. My committee member, Professor High, suggested it be valuable to ask my collaborators to share further details their recordings in order to make them more "real" in this thesis (personal communication, Jan. 4, 2019). In each of my conversations with the participants, I asked them to reconsider, in Frisch's words, "What is being talked about?" and "What are they saying about it?" (1990, p. 11). In doing so, I hoped to assist them in revealing more of their personal experiences related to Michael's passing, their connections to him, and their grief. I invited them to share additional insights with me about why they chose to speak about specific themes. In these discussions, my intention was, as Frisch explains, to explore wider topics by examining their individual experiences (1990, p. 59). I also thought these conversations could potentially be of benefit to my interlocutors. High recalls that one individual who took part in an oral history interview with him stated that the process helped to "understand himself better" (2017, Conclusion, para. 25). He also refers to another interviewee who indicated the interview "gave him a structure that has helped him to interpret his own experience" (2017, Conclusion, para. 25). I also asked my interlocutors if they found that the way we collaborated together helped them to share and record their testimonies.

By re-examining the participants' testimonies with them, my goal was also to provide additional information for the reader about the context in which the recordings were made. I think this is important, because publishing just five curated and edited recordings from each participant means that people who listen and engage with the digital memorial will have a

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limited understanding of the participants' individual motivations for producing and sharing their recordings and the sustained communication and negotiation that I had with them. Frisch claims: "We would miss much of the content, historical value, and meaning in any extensive interview were limited only to what is articulated in specific "sound bites" (1990, p. 83). He adds if a more nuanced context is communicated to audiences, it is possible that "bits and pieces can be assembled, and even reassembled, to represent that thought and information accurately for a condensed excerpt or in a digested narrative" (1990, p. 85). Along with asking my collaborators to share information about the points raised above, I invited them to examine any limits of the process that we engaged in, as they see them.

In what follows, along with sharing details of my conversations with my interlocutors, I present highlights of my autoethnographic reflections on their testimonies. Ellis argues: "Readers might want to be privy to the interviewer's reflections on her own story as she hears and/or tells the participant's story" (2004, Class Three, para. 50). Beyond relaying what may have prompted researchers to engage in particular projects, something I have previously done in this thesis, Ellis claims that "knowledge of the self" can be "used to understand what the interviewee says" (2004, Class Three, para. 50). Although I did not speak openly about my life with the participants, Adams, Holman Jones, and Ellis make a case for "look[ing] inward—into our identities, thoughts, feelings, and experiences—and *outward*—into our relationships, communities, and cultures." They argue that as researchers, there is value in taking "readers/audience through the same process, back and forth, inside and out" (2015, Chapter 3, para. 1).

### Carina's first recording: Papa, No Die

As previously highlighted, in this recording, Carina examines how one of her children was refusing or unable to accept that Michael had died, and how of one her older children was trying to tell him that he had. In our discussion<sup>24</sup>, I asked Carina what led her to record details of this moment, and what she was saying?

Carina responded: "Part of our struggle was that as a family, our children were preverbal. In that recording, he was just trying to make sense of that in words. I was describing the pain of a parent watching this unfold."

"Was it helpful to make this recording?" I asked.

<sup>&</sup>lt;sup>24</sup> The conversation with Carina was conducted by telephone on Feb. 3, 2019.

Carina recalled that in the months after Michael passed away, still grieving, with two young children, and then with a third, the only time that she had to make her recordings was in her bed late at night when the rest of her family was asleep. "I really did feel a lot of intimacy with my own experience and privacy," she said.

"Did you picture anyone in particular listening to your recordings?" I asked.

"I knew you would be listening, and I wasn't really imagining a particular audience, but I remember recording that. That's at the threshold of really intimate and really strikingly sad and captures a lot, and I remember thinking, 'Could I actually share that?"

I wanted to know more if she sensed that sharing personal details about her experience and her family's life felt beneficial to her in any way. She explained:

The process of sharing something really meaningful that would be listened to and be witnessed felt really meaningful, so I imagined sharing with you. Just being witnessed. My experience grieving was a little bit public, but about to have a baby and with kids at home, it was a very insular time, so those moments of being witnessed felt almost like a release, not just mine to hold.

It seems positive knowing that Carina felt that sharing intimate details of her life at a very difficult time was worthwhile to her. In spite of the disappointment that she expressed about the overall presentation of the digital memorial, a subject that I examine in more detail later on, I will remember her statements about feeling supported by me as I develop further participatory projects. Hearing this reaffirms my belief in the value of collaborative research, and statements such as these bolster my resolve to want to conduct further projects of this nature.

### My autoethnographic reflections

I remember standing in her narrow walk-in closet that my mother shared with my father, running my fingers along a wool sweater that she had left hanging after she vanished. The pots that she had used to cook our meals for years were still stowed in the kitchen cupboards. My father brought all her possessions — metal tubes of watercolour and oil paint, sable brushes, palettes and papers, the clothes she had left behind, their wedding album and photos of my mother wearing a white mini skirt, her hair in ringlets — down to the basement. I stood near the top of the stairs listening to him pack her belonging in cardboard boxes. The sound of him sealing them shut with packing tape felt deafening to me.

#### Carina's second recording: Ashes, Oceans, and Sunsets

Carina recalls transferring Michael's ashes from a box that she received from the crematorium into an urn. She was at the ocean's edge with her children, and some of the ashes spilled into the water, taking on unique formations lit up by the sunlight. Carina remembers the night before Michael was found unconscious in Victoria, their family had a picnic at the same spot. At that time, she watched Michael "throw himself" (Dec. 14, 2017) into the water.

In our discussion, Carina recalled: "I remember thinking, he's so brave. And she added: "Somehow since he died, that's easier for me to do, too. The thing that used to stop me was the fear of how cold the water was or the fear of being uncomfortable. Since his death, that doesn't show up. What's the worst thing that could happen? It's just cold water. Even the coldness feels different. It feels fresh."

The way Carina describes Michael diving into the ocean stays with me. The image of him leaping into the cold water feels unsettling, particularly because of how cold she said the water was. In our conversation about this particular recording, she referred to Michael as having "an openness to experience without proper boundaries," and a willingness "to experience what was in front of him."

She described this as something positive, and added that since his death, she has frequently leapt into the cold water as well. She said that she no longer feels the same trepidation that she used to about doing so, and she suggested this is because of what she learned from Michael.

As I listened to Carina, I wondered if the same fearlessness led him to take the opioids that ended his life. I recalled how she previously indicated that in his final moments of life, perhaps just as he had leapt into the water, Michael had been searching for some kind of relief.

# My autoethographic reflections

When I was a boy and my mother was still home, she used to try to get away from everything and from our family. There was a period when I was about nine-years-old when she stormed out of the house virtually every night, typically after shouting with my father and him pleading with her to calm down. Even now when I hear the sound of rattling keys, I remember my mother sweeping hers off the kitchen counter, slamming the front door, and backing the car out of the driveway. I have no idea where she went all those times. Did she drive around the neighbourhood in the same way that I wandered on foot after she vanished? Or did she stop somewhere near our home to gaze over the Ottawa River hoping for some kind of peace?

It seemed to me like my mother was always yearning to be somewhere else. When I look at photos of her when I was a boy, she often appears to be often looking into the distance, and I wonder if she was being tormented by her own thoughts and feelings. She used to tell me how much she loathed living in Ottawa, and dreamed of moving back to Vancouver where she grew up and said she felt the most connected to people. My mother complained about the black flies in the Ontario summers, the humidity, and the frigid, dark winters. She insisted the water that ran from the taps in Ottawa tasted terrible, and that the water in Vancouver was much cleaner and better to drink.

Many weekends, I sat in the passenger seat of our station wagon, and my mom drove us out of the city. When we reached the end of the highway, she took narrow roads and we were surrounded by endless fields. On these outings, she seemed at ease and whole, and I wished she would never turn the car around to go home.

# Carina's third recording: Life and Death

As noted previously, three weeks before her third child was born, Carina considers her looming delivery. She recalls in detail the night that Michael was found in his vehicle in Victoria after using opioids. She remembers watching the police approaching her house holding a flashlight, and how she knew before she opened the door what they would tell her. She explains the isolation she felt as she travelled by police boat to Victoria where she sat at Michael's bedside in hospital.

Carina then recalls a member of the medical team telling her that they were struggling to remove Michael's wedding ring, but they eventually managed to do so. She explains that his lungs and kidneys were removed for donation. Carina describes exiting the hospital down a flight of stairs that opened to a dark and unfamiliar place. She indicates that her father picked up her and brought her to his home where her children were sleeping.

In the same recording, Carina describes how at 35 or 36 weeks pregnant, her midwife discovered that Carina's baby was head up in the womb in breech position. Carina recalls having

to get an ultrasound, but the machine was broken. As a result, she was taken to the same hospital wing where Michael had died in order to have the ultrasound in another room. In her testimony, Carina recalls the moment she entered that space.

The content of the recording is very personal, and I asked Carina what inspired her to open up in this way in her testimony. She responded:

I was having a collected sense of the memory at that time, that evening. I recorded that one and I remember thinking, now I'm ready to articulate this and put this together. I guess it was this question for me with this project, how much can I let people in? Where is my limit of what is too personal? . . . That evening I felt really vulnerable and I felt really willing to share that with others. I felt really honest. I felt like I wasn't protecting other people from feeling my pain and feeling the complexity of our circumstances, waiting for the baby and having all of that story really strong and arising and so painful at that time. That was really my experience around the birth. I really had to digest a lot of that experience around Michael in the hospital in order to feel ready to have the baby. I didn't feel protective of creating another kind of picture of how our family is doing. . . . This is really big right now.

"You were really vulnerable," I said. "Was that helpful for you? What made you feel like you could be so vulnerable?" Carina explained:

Michael existed in the world where his personal life was not part of his image in the world image. His complexity wasn't that easy to perceive, and how our family lived with his complexity wasn't necessarily that obvious or visible. And so the image of him after death is easily static. . . . I feel like all of these stories add more dimension to who he is in the world, and even though those are our stories, they all add more depth to *him* as a person and as a deceased person. . . . The depth is necessary and the complexity is necessary.

# My autoethnographic reflections

By the time my son was born in 2015, my mother had known she had terminal cancer for at least a month, and she was already very ill. She had been in hospital and I had spent a lot of

time visiting her there. My wife, Bee, delivered our son at a different hospital on the other side of the city, but leading up to the birth, I continued to think about my mother and her failing health. I thought of the colour of the light in her hospital room in the late afternoon as the sun started its daily descent. I recalled how it cast my mom in a warm glow, and how I had watched her sleeping with her hospital blanket tucked under her chin, the drapes drawn around her narrow bed. At 7:30 in the morning when my son came into the world, the sun was already vibrant and clear.

My mother managed to gather the strength to come to the hospital after Bee gave birth. As Bee rested, I held my son in my lap and wrapped my free arm around my mother. I wished we could stay like that forever. When she died six months later, I carried my son in my arms through the cemetery before placing my mother's ashes in the earth.

### Carina's fourth recording: Beautiful Nightmare

Carina speaks about some of her most precious memories of when she and Michael began their romantic relationship. I have previously explored some of these recollections. She describes the first loft apartment in Toronto that they shared, which was also the dedicated space for Michael's meditation group that met there weekly. Carina remembers the green, vintage sofa that Michael brought home from a second-hand store. She says: "We spent the beginning of our relationship on that couch talking rubbing each other's feet. . . . We didn't tire of each other's company. We just wanted more and more of it. We could stay up like teenagers, lest we be chatting into daybreak" (Jan. 25, 2018). And she recalls how that sense of relishing each other's company never faded, and how they had spoken about that not long before Michael's passing.

I asked what prompted her to share these details in her recording. She said it was in part a way of acknowledging the sadness that she felt at the time, and of also making a statement that someone who was as complicated, loving, and loved as Michael could die of an overdose. She added:

My intention was to share more details and create some context for our life before, and as part of my grieving, things that I was reflecting on, and it's all letting go of having those beautiful parts of our life together present as a jumping off point to the future. It all becomes a question mark. It's really gone... Probably the biggest thing underneath it was sharing complexity and details. I think part of what that does is allow folks to identify with it or not, with falling in love, creating a home, and all these little details that are rich in one's life. And wait a minute, how could this have happened? And I imagine someone who's not in my family could say, this couldn't happen because this or that.

#### My autoethnographic reflections

The only time I have ever felt at home was in the years of my childhood before my mother developed bipolar disorder and disappeared. In her presence, I was able to relax and be myself. I felt protected and seen.

I watched her painting at wooden table in a small studio at the back of our house. I loved how she inhabited the silence and how it fueled her creativity. I looked forward to coming home from school to see her. She poured tea and we sat and drank it together, taking our time as if nothing would ever change. I went with her to the ByWard Market in Ottawa to buy homemade pasta. She listened to Leonard Cohen, took me skiing, and shopped for antiques at the Stittsville Flea Market. It is there that she bought our dining room table, the dressers where she kept her clothes, and my parents' brass bedframe, the objects and mementos that she would ultimately leave behind.

#### Carina's fifth recording: Here and Not Here

Carina examines her feelings of anticipation before having her third child, and how after the delivery, she felt nervous about bonding with him in light of Michael's recent passing. When her child was born, she saw that he looked a lot like Michael. Carina remembers: "I was learning him, studying him, and loving him, even though he looks like Michael so much. It was wonderful" (Feb. 14, 2018).

She also recalls how in the days after the birth, she often thought of Michael, picturing him in what she described as a state of being "half alive" (Feb. 14, 2018). She added: "I transition from that night [of his death] into nursing the baby or changing a diaper. I am processing these things: Michael leaving his embodied self, and transitioning to him not living, processing this over and over and over" (Feb. 14, 2018).

In the recording, Carina also explores her desire to keep hold of Michael's presence,

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combined with her repeated thoughts about seeing him as he neared death in hospital. I wanted to know why she felt inclined to share these details. In our discussion, she stated that while making her recordings, she was beginning to imagine an audience, and felt it was important to provide information about the wider circumstances of her life that she was facing. Above all, she said she wanted to communicate "what it was like giving birth to his baby." She added: "It could be so painful, but it was wonderful."

Carina indicated that her repetitive flashbacks of seeing Michael in the hospital led her to develop "a lot of anxiety and PTSD." She described feeling that "every night [she] was actively losing him over and over." Carina said that sharing her experiences in the project allowed her to feel "understood or held by others," adding that it felt like "a little puncture in the pressure—not really enough to lift it away from me, but helpful to feel it was shared."

#### My autoethnographic reflections

I took photos of my mother as she moved through her journey with pancreatic cancer, right up to the night of her death. The last image that I framed of her was just minutes before she took her last breath. I purposefully stored the photograph and others that I took of her on a hard drive, so I know where to find them if I ever want to. Sometimes, when I am looking for other files, the image of her close to death pops up on my monitor. Whenever that happens, I try to look away and close the window quickly. It always surprises me how painful it is for me to see what she looked like in that moment, so frail, with her head tilted to one side on her pillow. I took the image, hoping to preserve something — her aliveness and my connection to her — and now I can hardly bear to look at it.

I do not have to look at the photo to remind me of how she was in those final moments. Memories of sitting with her as she slipped away often appear in my mind without warning. I think of my mother's face just before she died when I am with my children. I could be giving them a bath or reading them a story before bed, and the memory will come. In moments like these, I feel that as much as I tried to be present for her as she died, there is still so much left so much loss — for me to process.

## Rose's first recording: Touching What is Tender

Rose examines how she is dealing with her grief about Michael's passing. She explores how her meditation practice allows her to understand how it is playing out in her mind and heart.

Rose also speaks of instances when the emotions become too challenging, and she needs some respite from them. She speaks of "touching" her grief, "and giving it a little bit of space" (March 11, 2018). She adds:

Sometimes that looks like sitting practice, feeling what is coming up for me and breathing with it. Sometimes it means I'm calling a friend. Usually I don't want to talk about him directly, but I need someone around so I feel supported in my process. . . . It's a body experience, this grief, like somehow I'm processing at a cellular level. Sometimes it's not so heavy and I can hold it a little lightly. . . . There's still communication happening . . . I can hear him saying, 'It's going to be okay.' (March 11, 2018)

In our conversation<sup>25</sup>, I asked Rose what she thinks her reflections say about her grief at the time she made the recording. She responded: "That I'm struggling. Grief is not a linear process. Just experiencing that — the cyclical nature of that grief, the ebbs and the flows, times when it didn't feel that oppressive — is kind of sweet in a way, sometimes pleasurable."

"Was it helpful recording this?" I asked.

Rose answered that she found it beneficial to "verbalize what was happening in my body and life."

I asked if she found that having Skype calls together and making her recordings this way was helpful for her, as opposed to creating her recordings on her own. Rose indicated that she found the method was helpful, and that she felt the connection we established together was supportive. But she added the process was not without its challenges.

I was already doing so much processing on my own, so being with you was helpful with that. . . . I felt that warmth. I definitely couldn't have had those conversations if we hadn't felt close. I felt safe, warmth, but I think there is another part of me. I wish I had more time with you. In the back of my mind, I didn't want to disappoint you.

"Because it was a PhD project?" I asked.

<sup>&</sup>lt;sup>25</sup> The conversation with Rose was conducted by telephone on Feb. 3, 2019.

"It had nothing to do with you," she stated. "It's my problem with being seen or heard in a particular way. I don't feel I'm very good at communicating what I feel, so I feel selfconscious about that."

### My autoethnographic reflections

After my mother died, I kept some of her paintings, and I have mixed feelings about these objects now. For now, they are in boxes in storage, and I wonder if I will ever be able to bring myself to take them out and place them on the walls of my home. When I feel positive about my mother and that my grief is manageable, I can picture myself doing this. Yet, most of the time, my pain still feels too raw, and I suspect that I will likely keep the paintings sealed in their boxes for a long time. To hang the paintings would mean being reminded of her daily and of the grief that still lingers.

One day, if I feel ready, I may take one of her pieces of art out. I might hold it and look at it. In doing so, I will do as Rose suggests, and "touch what is tender." For now, I take comfort knowing the paintings are sealed away.

## Rose's second recording: Joy Hidden in Grief, Grief Hidden in Joy

Rose recalls blowing out a candle on her alter and watching the flame come back up. As it does, she says she thinks of Michael "teasing her," and that she can almost hear him say, "Don't take it so seriously." She describes it as a "sweet moment" in which she "really felt him" (March 11, 2018).

She adds that there is an LED sign on a church outside her apartment, and it often says, "Don't be afraid," and, "I am always with you" (March 11, 2018). Like the candle that refuses to blow out, Rose says the sign reminds her of Michael. She says: "I feel like he's always around. He's showing up when I'm not looking for him to show up. He arrives" (March 11, 2018).

In our conversation, I asked why she felt it was important to share these moments in her recording. She responded by saying that she felt that it could potentially be beneficial for others who were connected to Michael to hear her express herself in this way. Rose added:

I think all of Michael's students feel that. When I talk to them, they feel him in their sitting, in their walking. They feel him in their every day. . . . I hoped it would be helpful for our meditation community. To know that their experience

was also my experience. I know from having conversations with other people, I think we share this experience of Michael after his death, that he's still around and alive with us, and I think it's helpful for people to know.

### Rose's third recording: Not Separate

In this recording, Rose explores how when she is outside in the city or in nature she is often reminded of Michael. "I can feel him in the elements," she says (Jan. 21, 2018). She adds that she has a strong sense of him when she is riding her bicycle, swimming, or practicing yoga. Rose describes the experience as sensing "no gap, no separation," and explains that is something "he talked a lot about (Jan. 21, 2018). " She adds that these thoughts and feelings can feel "overwhelming" (Jan 21, 2018) to her.

Rose recalls a specific day when she was riding her bike. She states: "It started snowing, and I could see the snow crystalizing all around me, and it somehow reflected or mirrored back to me the crystallization of Michael and his teachings inside me" (Jan. 21, 2018).

In our discussion, I asked if she felt it was beneficial for her to share that part of her life. Rose explained that as with other recordings, she hoped that speaking about her grief would also be of assistance to people in her meditation group. "I don't think I'm the only one with these type of experiences," she said. It also seemed to me that by reflecting on her recording, Rose was developing insights into her experience with grief. She stated:

I guess what I'm expressing in that recording is that grief, memory, and feeling and Michael's teaching, both spiritual and physical and yogic, still were continuing even though he's not continuing in a physical way anymore. I just keep circling back that even through he's not here, his body is not here, his teachings are still circulating. . . . I can't lose them. . . . They are in me and circulating like blood almost.

Rose also explained that she felt I was listening to her as she created her recordings during our Skype calls. "It helped that you were able to hold that with me," she said. "There are few people that I did talk about that with, but very few."

I indicated that I felt some people in my life were not able or interested in listening to me speak about my grief following my mother's death. Rose then said: "If people are not open or receptive to those experiences, I feel vulnerable and exposed in sharing. . . . If they can't hear it and hold it."

"Did you feel I was able to hear you? If so, do you have a sense of why?" I asked.

"I can't pinpoint exactly what it was," Rose responded. "I could feel your presence was right there. You can feel that with certain people. You don't need to know their background story. If they're distracted or present and able to hold it, I'll feel that."

## My autoethnographic reflections

Being in nature often makes me think of my mother. At times, when I am walking on forest trails or near the ocean, I feel her presence. In these moments, I have the sense that I have entered a painting that she could have created. I feel an appreciation of the beauty that surrounds me and an inner tranquility. At times like these, I do not feel the need to change anything about my past. In nature, I do not feel that she is far, even though I will never be able to hold her hand again or hear her voice.

## Rose's fourth recording: New Year, New Form

Rose talks about how following Michael's death, she spent the first New Year holiday in eight years without him (Jan. 21, 2018). She was used to going on meditation retreats with him over the holidays, and after his death, she accepted a friend's invitation and go to their New Year's Eve party. I have examined this recording previously, but in our discussion, I asked Rose why she wanted to explore this particular experience — how in the midst of the party, she found herself thinking about Michael. She stated:

I'm trying to process that life is still happening, and Michael's gone. It still to this day shocks me, when I think about him sometimes, or when I see his name somewhere, or Carina sends me a photo. I am still shocked that that happened. And I feel in that recording I try to come to terms with the fact that he's not alive anymore . . . It feels like no time has passed, like that just happened yesterday. . . . The grief is still happening, it feels a little less intense now, but still pretty intense. "As you say, it sounds like you were trying to come to terms with what had happened?" I said.

Rose added:

How can these two things exist — his death and my living? How do I continue when he doesn't? How does life keep going when someone is missing? . . . How can there be joy and he's gone? How do those two things live side by side? How do they hold hands?

# My autoethnographic reflections

When I was 19 or 20 years-old, I was invited to Thanksgiving dinner at my mother's sister's house in West Vancouver. She owned a beautiful home and it was a lavish meal. Throughout dinner, I could not stop thinking about my mom, who was still missing at the time. I watched the rain streaming down the dining room window, and I imagined my mother sleeping in her car and the vehicle filling with water. While I was safe and dry, I worried about her safety and well-being. How could I enjoy Thanksgiving when my mother's whereabouts and condition were unknown? How could I feel grateful and hopeful when I did not know how my mother was?

## Rose's fifth recording: The Bond that Can't be Broken

In her fifth recording, Rose reflects on the connection she shared with Michael. She states:

The bond beneath the grief can't be broken. The bond and the grief are trying to relate with one another, and sometimes the bond is trying to make contact with Michael in a way like when Michael was alive, and the grief is saying, 'Well, you can't do it that way anymore.' And the grief is overwhelming, because the bond is so strong. (March 11, 2018)

Rose also describes a disconnect that she feels. She describes having conversations with Michael in her mind and how she used to speak with him in person during their monthly meetings. "We would talk about what was coming up," she says, "But now there's no meeting. I think the grief is pushing up against that. I can't talk with Michael. He's not there" (March 11, 2018).

In our discussion, I asked what Rose wanted to share this information in her recording. She responded:

Reality wasn't matching up with what I needed or wanted. When somebody dies, you can't have it in that way anymore. How do you resolve that? I think all the recordings are about grief and how I'm struggling with hit. I think I'm talking about how I'm confronting the grief, or how the grief is confronting me. You have to find another way.

"A process of figuring it out as you went along?" I asked.

"I'm still figuring it out," she said.

Finally, I asked Rose how she felt about sharing these details through the project. She replied by saying she questioned whether people who listen to her recording will understand her feelings and grief. She concluded our discussion by stating, "I feel vulnerable in those recordings. It just feels a little scary that it is out in the world."

# Andréa's first recording: The Farawayness

Andréa talks about moments when she saw Michael, not only as a teacher, but visibly challenged by the pressures of daily life, raising children, and by mental illness. She recalls a specific moment when Michael was facing symptoms of bipolar disorder and she was at Carina and Michael's home. She remembers Carina telling her that Michael was having "racing and suicidal thoughts" (Feb. 12, 2018). Andréa opted to take their oldest son for a drive so he could sleep, and Carina called Michael's psychiatrist. She says Michael "was in another realm" (Feb. 12, 2018), and although he sat beside her on a couch, she was not able to connect with him. Andréa then describes travelling with Carina and Michael to the hospital, but by the time they arrived, Michael was feeling better, so they returned home. She adds: "Seeing him struggle and Carina confiding in me and being a support, I had a more realistic sense of his struggle and a broad sense of his moods — what a beast bipolar can be and how strong the mood shifts can be" (Feb. 12, 2018).

In our discussion,<sup>26</sup> I asked why she felt inclined to speak about these moments in her recording. She said she imagined members of the meditation community that Michael formed listening, and she thought it might be helpful for them to hear her memories and insights. She said:

I wanted to shed a little light on what had happened. . . . For me and Carina, [his death] was a surprise and not a surprise. . . . We had seen him struggle so much. . . . Carina said one of the most valuable things I could share was having been close to their family. . . . Most people had seen him mentally stable, but I had seen him with mental instability. So it felt like that was important to give a broader perspective of what day to day life could be, shining light into the realness of mental illness. At first it was surprising, and there were other moments when I was near them of mania or depression. I have so much compassion for Michael and Carina and her ability to raise her kids and have her partner be in a state of difficulty.

I enquired whether the method in which she produced her recordings was helpful and allowed her to share personal details. Andréa stated: "The biggest limitation I felt was figuring out what to share and what couldn't—how to be honest but how to be respectful of the experience." She had previously explained that she was initially not sure how Carina would feel about her speaking about Michael's experience with mental illness in the project. She reported that Carina had told encouraged her to speak freely.

I then asked if she had any reservations about making herself vulnerable in her recordings. Andréa said:

I'm used to sharing my heart and thoughts as an artist. It's all about being vulnerable, and a big part of meditation practice is being honest and not creating a field of apparent perfection or 'having it all together.' It felt intimate enough. I would be different if I was to speak in front of 300 people, but in the recordings, in my house or outside felt comfortable.

<sup>&</sup>lt;sup>26</sup> The conversation with Andréa was conducted by telephone on Feb. 2, 2019.

I questioned if she had considered that many people might listen to her recordings, and if she had, how she felt about that. She responded: "I didn't think about that while recording. I felt more connected to the people I know who would appreciate hearing."

### My autoethnographic reflections

When I was a boy, I trusted my mother more than anyone. She repeatedly told me that she was being poisoned. I could not begin to understand what she was saying. It was much too sinister for me to visualize in my mind. All I knew was that she felt unsafe and threatened.

My father went to work in the morning and came home in the evening. I went to school, rode my bike with my friends, and did my homework. The whole time, my mom feared for her life, even as she painted in her studio and took day-trips with me out of the city, until she could not take it anymore and she left.

What is it like loving someone with a mental illness? It is a pain unlike any other I have known. As a young person, I learned I had no control over the fluctuations in my mother's moods and thoughts. While she was still at home, and in the years that she was missing, all I could do was hope that someday the paranoia that gripped her would somehow subside.

#### Andréa's second recording: Moments that are Simple, Moments that are Complex

Andréa made her second recording months she had travelled from her home in Mexico to stay with Carina in B.C. in order to be there for the birth of Carina's third child. She describes her intention "to serve this little family, to be able to support them—making breakfast, giving a calf massage, cleaning pee and food from the floor" (Dec. 26, 2017). Andréa recalls that being at Carina's home felt like being on a meditation retreat. She says: "An element of service that feels good and natural and exactly what this practice that we do, which is to show up to each other's lives in moments that are simple and moments that are complex" (Dec. 26, 2017).

During her stay with Carina's family, Andréa also remembers being present for the birth of Carina and Michael's first two children. She describes thinking how Michael was so helpful in those moments, how he "got food on the table, played with the kids, and was tender to Carina" (Dec. 26, 2017). Andréa then explains that in light of Michael's death, she wondered if she would be able to help Carina in the way that he had. "I realized how much we needed Michael, but I channelled that capacity to feed everyone like Michael did," she says. "We'll be fine, but I miss his cooking" (Dec. 26, 2017).

In our conversation, I asked, "What were you trying to say?" Andréa responded:

I think I was appreciating being able to be nearby. When you're far from someone you love, and you want to be of help, and then finally being there physically with your body and being able to support them — a feeling of relief of being useful and reprocessing — not being with an idea of what was happening but being with what was happening.

I then questioned whether Andréa found it helpful to make this recording. In response, she stated that rather than considering how the project could potentially benefit her, she was interested in being "helpful for others," by sharing her perspectives on mental health. I asked if she could say more about her intentions.

She replied: "To give a broader view. How it's lived on the inside. In sharing, you can give insight into the different layers of a person's life, including their mental health — the struggle, but also the poetry, the magic."

"But why?" I asked. "To disrupt stigma about people with mental illness and those who overdose?"

Andréa stated that she felt excited to participate in the project in order to help provide a fuller picture about Michael's life than journalism organizations had communicated. She added that she wanted "to show that he was a human living with mental health issues, and so just to share that broader perspective, which I think Michael was leading up to but wasn't ready."

### Andréa's third recording: Grief is only as Big as the Relationship Was

Andréa explains that in her view, "the closer you are [to the deceased], the more intense the emotions can be" (March 18, 2018). In spite of the magnitude of the grief she felt in the aftermath of Michael's passing, Andréa claims the Buddhist teachings that Michael shared with her, enabled her to be with these challenging experiences. She adds he "talked about emotions being guests inside the house. Not to block them. To recognize them, including anger and grief. The idea is those guests don't stay forever, and the key is to allow them to go out" (March 18, 2018).

I wanted to know more why she shared these thoughts in her recording, so enquired

during our conversation.

"There was a beauty," she said. "Like poetry. The person who taught you to let go. Then you have to let go of that person."

### My autoethnographic reflections

My mother taught me about kindness and compassion. I learned from her not to judge others and to accept differences. She had an open and generous heart, and I took after her when I was young. When she developed bipolar disorder, before leaving our family, she lost all of her friends. Many turned their backs on her. They were fearful of the unknown, and they no longer wanted her in their lives. It felt like a betrayal to her, and she was devastated.

I recognize that mothers who abandon their children are widely demonized, but I never saw her in a negative light because of the decisions she made. I always understood who she truly was. I saw through her mental illness, and knew she was well-intentioned, loving, and wanted to express herself and feel free.

### Andréa's fourth recording: How the Light Changes

Andréa recalls the moment when Michael was in hospital in Victoria and close to death, and she was on the other side of the country in Gaspé, QC. She was on a long-planned road-trip with her father, and one evening, she took time to say goodbye to Michael from afar. She remembers:

My dad and I made a fire on the beach, and we both sat and meditated together, and watched the sun go down, and I cried so much. I felt our friend was going on a great voyage and I really wanted to wave goodbye to him, to wish him good fortune and to send him off for the great leap forward into the biggest mystery. So that day when we were sitting by the sunset, I just lifted by arm and wished him such a good voyage and trust and bravery and told him to go to the light, to feel the freedom, to enjoy swimming in the ocean, flying in the sky, being any animal he could be, being absolutely one with this big mother, this big earth. That was really healing to wave. I felt that was really necessary. (Dec. 26, 2017)

In our discussion, I asked: "Did the process help you to say goodbye?"

Andréa explained that making the recording allowed her to put her experience of saying goodbye to Michael into words. She added that the questions I had sent her early in the project encouraged her to express herself. Andréa said: "It helped me get to deeper levels, and it felt wholesome, grounding, and beautiful. In a way it created more depth that in the way that you have a conversation. As you are talking, different ideas and memories emerge."

### My autoethnographic reflections

The night my mother died, I sat at her bedside with the door locked. I needed time to be with her by myself. In the silence, after her breath had subsided, I said goodbye. I told her how strong she had been for years, and how I was proud of her and loved her. Before she passed away, I imagined her leaving her body behind, and her essence coursing through the universe. Yet, in that quiet space, I did not have the sense that she travelled far. Instead, I felt her leap from her body into mine. I never expected that, but in that moment it made sense. In spite of all we had been through, I was a safe harbour for her. Rather than having to face what I anticipated would be a final and torturous separation, I simply got up and carried her spirit with me.

## Andréa's fifth recording: Letter to the Sangha

Andréa reads a personal letter that she wrote to members of the meditation community that Michael established that she cherishes. Sangha is a Pali and Sanskrit word that refers to "a community that joins and lives together" (Berzin, n.d.) It is also used to describe Buddhist monks and nuns, but is increasingly used in the West to refer to the broader community of spiritual practitioners.

In her letter, Andréa remembers how Michael told the meditators, "Everything passes" (Aug. 7, 2018). She explores how her grief changes over time. "The heart rips open and then heals," she says. "This grief, too, is impermanent. I felt the least suffering when I didn't resist what was happening." She adds that "Michael is present in my every day, whispering into my ear, 'Slow down. Use both hands. Keep going" (Aug. 7, 2018).

"What was your intention and voicing the letter?" I asked.

"I think I needed to write this letter," she responded. She described it as "a letter of love" about "clicking and insights arriving and wanting to share that, and remembering it for me when I'm not so settled in my practice."

### Conclusion

This chapter began with a discussion of how a select number of interactive projects that feature audio testimonies as central elements led my collaborators and I to conclude that making audio recordings of their experiences was an optimal way to construct the project and create content for a digital memorial for Michael. I explained how my interlocutors used technology to create their recordings and the frequency of our communication. The majority of the chapter focused on an analysis of the participants recordings. This began with my reflections on how I view the women's testimonies as counter-narratives. I also presented highlights of feedback that two test listeners shared about the testimonies. I then discussed of the notion of crafting grief and continuing bonds theory. I explored how I invited the participants to engage with these concepts, and how doing so influenced the nature and content of their testimonies. I wrapped up the chapter with a more extensive analysis of my interlocutors' recordings. I shared details from my conversations with the participants about the themes they chose to examine in their recordings and about what led them to speak about particular issues. I also presented some of their thoughts about how they found the ways that we worked together helpful in producing their testimonies. Finally, I shared how my interlocutors' testimonies led me to experience a range of emotions, and I reflected in an autoethnographic manner on my personal history connected to my mother.

In Chapter 5, I briefly examine the concept of interactivity, and I explore my rationale for using the interactive application, Klynt, in order to construct the digital memorial. I highlight some of the benefits and drawbacks of interactive work, and how two particular interactive projects served as guides for our work together. I also highlight how I designed the memorial with my interlocutors and how they curated and edited their recordings. I draw on the concept of "difficult knowledge" to examine some of the ethical and practical issues that I had to consider. I also examine how I briefly considered inviting other individuals to contribute to the project, and how I ultimately recommitted to working in participatory ways with the project's three original participants.

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## **CHAPTER 5:**

# MEMORIALIZING MICHAEL: CREATING THE ONLINE PROJECT

## Introduction

In this chapter, I present a brief definition of interactivity and examine why I chose the interactive application, Klynt, in order to create the online project. I explore some of the advantages and limitations of interactivity, and how my collaborators and I used two participatory and interactive projects, *The Quipu Project* (Lerner & Court, 2015) and *Blood Sugar* (Daniel, 2010), as models for our work together. I discuss how I conceptualized the digital memorial and how my collaborators created parts of the project in order to archive and showcase their testimonies in unique and personal ways. The chapter also explores how the participants curated and edited their recordings. I discuss how I view their testimonies as "difficult knowledge" and how disseminating content of this nature raises a number of ethical questions. I recall my thoughts about sharing authority with my collaborators at the start of the project, and explain how my position on the matter shifted by considering how filmmakers associated with CFC/SN worked with members of marginalized communities. I conclude the chapter by highlighting how I responded to a host of other ethical and procedural dilemmas.

## **Building the digital memorial**

As outlined in the previous chapter, my collaborators and I decided to build a web-based interactive project in order to archive and disseminate their audio testimonies. There is an entire body of literature on interactive documentary, and it is beyond the scope of this thesis to examine these sources in detail, primarily because the project is framed as a digital memorial. Most of the research that I conducted focuses on testimony, reflexive anthropology, counter-memorials, digital memorialization, and more. However, I want to briefly present some information about interactive technology in order to highlight why it is an appropriate medium for this project.

Interactive technology is allowing researchers and media producers to make interventions and challenge social power relations outside of the frameworks of large institutions such as the NFB. Scholars and media makers have used interactivity in order to engage a wide range of participants and audiences. They have also utilized technology to encourage users to advocate for social change and take actions on their own.<sup>27</sup>

Sandra Gaudenzi explains that what sets interactive projects apart from linear media projects is that users begin at particular points. Users are then able to make choices about the content they want to consume by clicking. Projects are responsive in the sense that narratives and the media that are presented changes based on the choices that users make (Gaudenzi, 2003, p. 94). Gaudenzi uses the term "hitchhiking" (2003, p. 47) to describe the way media is linked within interactive or data-base projects. Users may have the impression they can make an unlimited number of choices, but creators can only formulate or choose from a limited number of options (Gaudenzi, 2003, p. 97).

Gaudenzi notes that interactivity is suitable for projects that examine people's lives, such as the digital memorial that we created about Michael. She asserts that interactivity could "in principle" allow users to learn about new people without feeling anxious about coming up with questions to ask them (personal communication, Dec. 1, 2018).

### Klynt as a platform

Although I have long worked as a journalist and documentary maker, I do not have experience with coding, and neither do the participants. Therefore, we needed a relatively straightforward way to create the interactive project that did not involve hiring designers and coders. A number of interactive editing and publishing applications are available.<sup>28</sup> Reading about these tools and exploring projects that have been made with them, I was drawn to use the software known as Klynt. Originally, most people who used Klynt included reporters, photographers, and film producers. It is now one of the most popular applications and is increasingly being utilized by a diverse range of people, including researchers, to produce non-linear database narratives (McIntyre, n.d.).

<sup>&</sup>lt;sup>27</sup> Some examples of recently produced interactive projects include: *Localore: Finding America* (Air Media. (n.d.)., which aims to encourage people in the U.S. to become interested in public media and enterprising forms of storytelling; *Treehugger: Wawona* (Marshmallow Laser Feast, Steel, & Ersin, n.d.) employs virtual reality in order to generate awareness about the environment and the need to protect trees; and *Immigrant Nation* (PBS, n.d.) highlights the stories and experiences of a range of people, tracing their family histories of immigration to the US. <sup>28</sup> Some of the best known web-based publishing applications include AngularJS, Creatavist, Explory, Frame Trail, Exposure, Interlude Treehouse, Korsakow, OdysseyJS, Pageflow, Popcorn Maker, TimelineJS, Racontr, Zeega, and others. http://www.i-docs/org/2014/07/15/interactive-documentary-tools/

One of the major incentives that I discovered about using Klynt is the program allows producers to create projects with different types of media, including images, video, text, and graphics. This was ideal, because along with audio-recorded testimonies, my collaborators planned to incorporate images and text in the project.

### Affordances of interactivity

As noted in previous chapters, the NFB's CFC/SN initiative is widely recognized for its emphasis on involving the participation of marginalized and alienated communities and facilitating dialogue among documentary makers, decision makers, community leaders, and publics (Waugh, Baker, & Winton, 2010, p. 4). In spite of its goals, Marchesseault (1995) argues that CFC/SN largely failed to produce genuine agency, largely because of its top-down nature.

The emerging medium of interactivity is allowing researchers, media makers, and citizens to collaborate in innovative ways (Miller & Allor, 2016, p. 2). Yet, supporting truly democratic and participatory work requires that scholars and media makers consider their approaches. Miller and Allor cite media producer and scholar Sharon Daniel, who claims that interactive technology is allowing her to shift from taking on the role of director to acting as a facilitator, curator of knowledge, and "interpreting reality" (2016, p. 4). Like Daniel, Cizek believes that, as a media maker, her role is to be a "cultural animator" (Miller & Allor, 2016, p. 7) who facilitates partnerships and creative work. Miller and Allor also refer to Siobhan O'Flynn, who works as a consultant on digital, interactive, and participatory media creation. In Miller and Allor's words, she asserts that interactive producers increasingly assume roles of "organizer[s] and designer[s]" of online environments that are sufficiently broad in order to react and chronicle important issues (2016, p. 4).

Within larger organizations, producers are using interactivity to collaborate with communities, and this requires a shift in their methodological approach. Media producer jesikah maria ross says many different types and levels of collaboration are possible when it comes to interactive projects. She refers to this as "continuum of functional participation" (qtd. in Miller, 2009, p. 72). Ross argues that participants need to know exactly what they are agreeing to before getting involved in initiatives whose methodologies rely on interactive technology. She adds that people must be able to decide for themselves how little or how much they want to be responsible for.

Engaging in interactive work that enables collaborators to develop agency is difficult but beneficial. De Michiel and Zimmerman have theorized about an evolving way to do so. They argue that interactivity allows media makers to move beyond thinking of their projects as completed objects as they are used to doing. They coined the term "open space documentary" to describe interactive projects that can continually grow and change if different individuals and communities are given opportunities to do to contribute to them.<sup>29</sup> They claim that creating projects like this requires considerable engagement and dialogue with participants, a commitment to hearing and understanding different people's perspectives without judging them, and a willingness to test out new forms (2017, p. 3).

As I outline below, I briefly considered expanding the digital memorial for Michael in order to make it an open space documentary. Since thousands of people have been affected by the opioid crisis, a project of this nature that invites many people's contributions could be valuable and help to humanize individuals who die as a result of drug use and resist dominant narratives about the situation. I presented the idea to my collaborators, but they told me they were not in favour of it. I understood and supported their position. To invite others, and potentially people who did not know Michael, would have changed the project in considerable ways. My collaborators' requests that we keep the digital memorial small and include only their testimonies made sense in light of the nature of this project.

### Limitations of interactivity

In spite of the affordances of interactive technology, scholars point to a number of challenges and risks and that come with creating interactive projects. Some have noted that companies that develop and own the tools of production are able to claim ownership of projects and track producers' actions online as well as the content they use (Juhasz, 2014). Media projects

<sup>&</sup>lt;sup>29</sup> One example of an open-space documentary is *A Journal of Insomnia* (NFB, 2013), a crowd-sourced interactive documentary produced by the NFB that allowed people to record and submit web-cam journal entries about their experiences with insomnia. In curating these testimonies, the NFB (2013) claims it hoped to illustrate how insomnia is not an "individual problem [but] is in fact a collective experience." In opening up the project to wider participation, the NFB attempted to "incorporate a range of perspectives and broaden the social imagination" (De Michiel and Zimmerman 2017, 7). Other open space projects include *Lunch Love Community* (De Michiel, H. (2014), which is about food justice in communities and schools. Another example is *Saving the Sierra* (Ross, j. m., & Stifter, C. (2008), which focuses on preserving the environment in the Sierra Nevada region in California.

created by powerful production companies are unlikely to lead to social change, because these entities and their work processes reflect power imbalances and inequalities in society (Hindman, 2009). Miller and Allor contend that producers can effectively support change, not necessarily by developing technologically-sophisticated projects, but by focusing on achievable goals and collaborating with others in meaningful ways (2016, p. 15-16). Creating clear dissemination strategies that are suitable for projects can also help reach decision makers and citizens, and this can encourage change (McLagan & McKee, 2012).

Another concern about interactive projects is that users do not tend to stay on websites for very long. Most people now spend an approximately five minutes exploring online projects, and only a quarter of people return after they have visited for the first time (Epstein & Knowlton, 2015, para 7). Adults are able to stay engaged with interactive projects such as *86 ½ Years* (Usborne, 2017) and *The Quipu Project* (Lerner & Court, 2015) that are primarily constructed with audio content and use a limited number of images (Ross & Funari, 2017, p. 288). Younger people, however, prefer to engage with a range of media and at a relatively fast pace. *Losing Michael* invites users to take time listening to the participants' testimonies and examining a select number of images. I recognize that the project will unlikely appeal to all individuals, including younger people, who are not open to experiencing the memorial at a relatively slow speed.

Miller and Allor argue that one way of dealing with rapidly diminishing attention spans is for digital media makers and scholars to produce work on a range of platforms (2016, p. 2). They also remind scholars and media producers that not everyone has access to computers or devices in order to engage with digital and interactive projects (2016, p. 2). Cizek collaborated with a number of media organizations in order to disseminate her interactive project, *Highrise* (2009), on a number of platforms. It was published online by the NFB and *The New York Times*. After CBC Radio's Toronto morning show, *Metro Morning*, broadcast their three-hour program from a Highrise building, the online project received considerable attention from digital designers and others.<sup>30</sup> Other interactive producers have adopted multi-platform approaches to publishing projects. For example, the NFB, which produced the interactive documentary *Fort McMoney* (2013), made arrangements with *Le Monde* for the newspaper to present information about the project on its website (Miller & Allor, 2016, p. 13). The result was that more people learned about the project and ultimately explored it online.

<sup>&</sup>lt;sup>30</sup> For more information, see: http://highrise.nfb.ca/2012/02/live-radio-broadcast-from-highrise/

Midway through the project, I submitted a proposal to CBC News to produce a podcast that I envisioned as an extension of the work that I conducted with my collaborators, although I did not receive a response. I have considered planning public presentations and discussion forums that could allow a wider range of people to experience the digital memorial. However, given time and funding constraints, my interlocutors and I have opted to disseminate the project strictly online on its dedicated website. As Miller and Allor argue, this will limit the number of people who learn about the project and ultimately restrict its ability to affect change (2016, p. 2). As I discuss in the following chapter, I will reach out to a number of media organizations and invite them to interview the participants and me about the project. This is not the same as publishing the digital memorial on our own on different platforms, but it is a strategy that scholars and media makers, including the NFB with *Fort McMoney* (NFB & Dufresne, 2013), as noted above, frequently use in order to generate greater awareness about their work.

### **Participatory and interactive projects**

I want to highlight how the scholar-producers behind two particular participatory interactive projects intervened in critical and under-examined social issues and amplified the voices and experiences of marginalized people by helping to record and disseminate their audio testimonies. The creators of *The Quipu Project* (Lerner & Court, 2015), used digital technology in order to share testimonies of women who experienced forcible sterilization.

As mentioned previously, *The Quipu Project* (Lerner & Court, 2015), was constructed in order enable women who were forcibly sterilized to resist dominant narratives and shatter silences that have been imposed on them. The project's creators built upon Sturken's argument that technology is able to "embody and generate memory" (1997, p. 10). By recording and sharing their testimonies, the project's participants highlighted the Peruvian former government's role in the rights violations (Brown & Tucker, 2017, p. 8). The counter-narratives that the women created consist of a "range of voices, memories and perspectives that have been marginalized in dominant cultural memory" (Brown and Tucker, 2017, p. 5). Tucker and Brown insist that the women who took part in the project not only produced a historical archive about their experiences with forcible sterilization, but created "meaning about their world and their past experiences" (2017, p. 11). It has helped the women to feel empowered and given them a sense that they are finally being heard by others in Peru and abroad (Tucker & Brown, 2017, p. 12).

Like the CFC/SN filmmakers, the creators of *The Quipu Project* (Lerner & Court, 2015), aimed to create connections with wider publics, involve them, and invite them to respond (Tucker & Brown, 2017, p. 12). The testimonies that are shared through the project are not delivered to audiences in a "pure or unmediated form" (Tucker & Brown, 2017, p. 12). Users are required to engage and interact with the project, and this is intended to heighten people's understanding of the history and politics that shaped the women's experiences and testimonies (Tucker & Brown, 2017, p. 12). Tucker and Brown argue that "digital tools and networking technology" can be used in deliberate ways in order to reach "political and ethical ends" (Tucker & Brown, 2017, p. 13-14), and that these can go hand-in-hand with scholarly, participatory, and interventionist work. They add that digital design must be fully integrated into project planning from the outset in order for it to align with the wider "political and ethical" orientations of research projects (Tucker & Brown, 2017, p. 14). They insist that technology can never replace deep and meaningful connections between researchers and participants. Lastly, they contend that people's stories and testimonies that are not often heard can play a central role in shaping digital designs.

I viewed *The Quipu Project* (Lerner & Court, 2015) as a model for the digital memorial that I created with my collaborator, because it centres the women's experiences. Its creators wanted listeners to hear the participants speak in their own voices, even if they did not understand their languages (Mitchell, 2015, p. 7). The scholar-producers did not use voiceover translations and chose to transcribe the recordings instead. They were mindful that not all users would be patient enough or willing to listen to the women's full testimonies. Yet, they concluded that the "raw sound" (Lerner & Court, p. 9) of the women speaking through the phone system was compelling and would likely encourage people to explore the project. In order to heighten users' experiences of the initiative, the project's producers added visuals of the physical environment in Peru (Tucker & Brown, 2018, p. 9) and created compelling graphics of *quipus*. Although the project has been showcased in public, its producers designed it so the majority of people who experience it are able to listen to the women's testimonies in their own settings using their choice on smartphones or desktop computers. According to the creators, this adds to the "intimacy" of the project (Tucker & Brown, 2017, p. 9), and that it would have been less so had it been exclusively presented in museum settings.

In *Blood Sugar* (Daniel, 2010), another interactive project that influenced my project, that I referenced in earlier chapters, Daniel used digital technology as a means of archiving and

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disseminating audio-recorded testimonies with women who are incarcerated in prisons in California and who have experience using injection drugs. Daniel's goal was to collect and share testimonies of women who are seldom heard in mainstream society. She also wanted to draw attention to the "social and economic injustices" (2012, p. 217) that have impacted the women in a number of different contexts, including the judicial, health, and education systems. In doing so, she hoped to generate empathy for the participants and encourage wider "social and personal change" (2012, p. 217). Daniel claims that by archiving and disseminating a collection of recordings, she was able to invite listeners to view the participants not as flawed individuals, but to recognize how they are discriminated against and oppressed (2012, p. 217). As a group of testimonies, the project challenges the notion that drug addiction is a problem that occurs in isolation. It is, rather, the result of systemic issues, including racism, poverty, sexism, mental illness, and more, that affect large numbers of people.

Audio-visual projects that provide all of their content in linear ways can lead to passive or uncritical spectatorship. In contrast, Daniel purposefully orchestrates interactive experiences that facilitate users' engagement with participants' testimonies and issues they deal with. She argues that the interactive nature of her work allows users to "find [their] own way – to navigate a difficult terrain, to become immersed in it, and thus to have a transformative experience" (2012, p. 218). Daniel constructs her projects' interfaces and uses data as "argument[s]," (2012, p. 218) similar to those that traditional researchers make. She claims that the manner in which users experience her projects is a form of "enquiry" (2012, p. 218), which allows them to consider and come to their own understandings of participants' testimonies. *Blood Sugar* (Daniel, 2010) enables people to listen to full, unedited interviews. Users have the option of choosing which recordings to listen to and which parts of the testimonies they want to hear. They can also "zoom in and 'get closer' by clicking" (Daniel, 2012, p. 223). Daniel explains that the invitation for users to "zoom" in is a metaphor for her belief that people must not turn away seeing and ultimately understanding the "lived experience" of chronic and marginalized individuals who use drugs (2012, p. 223).

Another project that inspired our memorial was Martin Usborne's 86 ½ Years (2017). It features a number of audio recordings of Marcovitch speaking about a range of themes, including "walking," "relationships," "the important things," and more. 86 ½ Years (Usborne, 2017) begins with an abstract image of small floating particles set against a grey backdrop with soothing instrumental music. A photo of Marcovitch wearing black glasses and a sports jacket,

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standing in front of a wall spray-painted with graffiti, slowly appears. The title of the project, *86* //2 Years (Usborne, 2017), also fades up on the screen and users are instructed with a text-based cue to hold the spacebar to begin. From there, Marcovitch's photo partially fades away and users are presented with a further invitation to continue navigating the project. They can use a webcam, although this is not required. Next, a black and white photo of Marcovitch and Usborne appears, and the user hears Usborne recalling how they first met. People are then prompted to hold the spacebar to select different themes and recordings. When the spacebar is released, audio recordings of Marcovitch and brief commentary from Usborne are heard. Different images of Marcovitch also fill the frame.

## Planning the online project

My intention was for my collaborators and I to mutually design a digital memorial that would encourage users to engage with the project and explore it in depth. I imagined a design that would provide plenty of choices for users in terms of content, and that would be easy to navigate. As noted above, my major inspirations for creating the design were *The Quipu Project* (Lerner & Court, 2015), *Blood Sugar* (Daniel, 2010), and above all, *86 <sup>1</sup>/<sub>2</sub> Years* (Usborne, 2017).

Halfway through the project, I created a rough outline for the digital memorial. Using a pen and paper, I made sketches on 10 cue cards. I shared images of these drawings with my collaborators and invited them to offer feedback. My sketches representing the opening page of *Losing Michael* included an image of stars, and I wrote the words "soft, alluring music." On my second card, I suggested a fade up on the project's title. On the third card, I proposed using an image of Michael. I also noted an "About" button that would lead to a separate text-based summary of the project, and a "Share" button that would enable people to pass the memorial on to others via email and social media. On the fourth card, I drew an image to represent a photo of Michael and Carina. I suggested that users could then automatically hear a short audio recording from Carina describing the purpose and scope of the project and inviting people to listen to her, Rose, and Andréa's testimonies. On the fifth card, I simply wrote "Carina's story," "Rose's story," and "Andréa's story." I intended this to be a place where users could choose which recordings they wanted to listen to. I left the sixth, seventh and eighth and cards blank in order to represent the three participants' individual sections of the project where their recordings and images would be stored and showcased.

The participants expressed satisfaction with the overall vision I had proposed. As we continued to work together, the fundamental structure of the design did not change. However, all of the participants made specific requests about the images they wanted to use in the sections of the project focused on their testimonies. Carina had several recommendations about images of Michael that she felt were appropriate for the opening of the memorial. She also provided a black ink drawing that she had asked a friend to make for her portion of the online project. The image represents the home she shared with Michael and their children. In the picture, the front door is partially open and there is a child's drivable toy racing car and a pair of straw brooms leaning against a wall. The drawing communicates a feeling of warmth and suggests that the user is being invited to enter the home and explore Carina's recordings.

Rose indicated early on that she wanted to create an enso, a partially-completed circle and symbol traditionally associated with Zen Buddhism, as the prominent image for her section of the memorial.<sup>31</sup> The idea felt fitting to me in light of Rose's commitment to meditation, her connection to Michael as her spiritual teacher, and her experiences with grief. Rose bought a paintbrush, ink, and paper and sent me an image of an enso that she created. I was grateful that she had gone to the trouble, and she had clearly made the enso with great care. At the same time, I thought it looked too polished for the project. The ink that formed the circle was thick and consistent from start to finish, and to my mind it did not fully reflect Rose's grieving process as I had witnessed it over many months. I shared my thoughts with her and asked if she would be willing to create another enso. She agreed with me and said she would be pleased to make another one. A few days later, she emailed me a second enso. It was beautiful, had character, and I felt that it more accurately reflected her journey since Michael's death.

<sup>&</sup>lt;sup>31</sup> Master enso painter and Zen teacher, Kazuaki Tanahashi explains: "The enso—the Zen circle conveys everything, the whole world, absolute enlightenment, strength and elegance. It is the ultimate Buddhist Zen symbol of emptiness. The one stroke painting is an expression of the moment when the meditative mind and body meet to create" (n.d.).



Fig. 2. Rose Riccio. "Enso." (2018).

When I examine Rose's enso, I detect a boldness, energy, and momentum of the brush on paper where she begins the painting. To my mind, the enso reflects how Rose embarked on this project in a deep and meaningful way, and faced her emotions in the wake of Michael's passing. The right-hand side of the circle is solid. The ink has landed on the paper thickly and almost completely uniformly. The left-hand side of the enso is rougher. The ink that forms the black line is relatively thinner in this area. The brush's bristles have left thread-like traces in places. Where the ink is sparse, I am reminded of instances in our conversations when Rose expressed sadness, a yearning to relive significant moments that she shared with Michael, and instances when she said she was fed up with grieving and wanted a break from it.

The ink becomes thick again, reflecting perhaps a second-wind or renewed commitment, before it trails off, leaving the circle unfinished. In the small gap between the start of the enso and where the ink ends, I detect further movement and energy, not a sudden drop-off into oblivion. There is the suggestion of continuity. I am unable to intellectually interpret this space in the enso, the gulf between where the ink starts and finishes, but the emptiness feels alive to me. I recall that Rose asked herself in one of our conversations, "Where does Michael live now? What kind of space does he live in?" (personal communication, Feb. 11, 2018). By making her

enso, engaging in consistent reflection and meditation, and by sharing her thoughts and feelings in her recordings, I suspect that Rose is getting close to revealing the answers for herself.

For her part, Andréa created a series of intricate embroideries in order to provide visual backdrops for each of her audio recordings that are featured in the memorial. She made the designs by hand-stitching abstract images with white thread on pieces of blue cloth. She then photographed the embroideries, edited them so they appear in circular formations, and shared them with me. These visual representations are unique and compelling. One of embroideries represents mountains, and Andréa asked that it be paired with her audio recording that she named *The Farawayness*. In this particular recording, she describes how Michael no longer feels as present to her as he did immediately following his death. In another embroidery, a number of cell-like structures appear to be growing and rising up from the lower part of the frame. Andréa requested that the image be published in the memorial with a recording that she named *Bipolar Beast* in which she recalls witnessing Michael struggle with his mental illness. Andréa's other embroideries feature triangle-shaped designs, patterns that look like flowers, stars, and more.



Fig. 3. Andréa de Keijzer. "The Farawayness." (2018).

# Curating "difficult knowledge"

As I listened to my interlocutors' recordings, I found them engaging. For a time, I thought there could be advantages to disseminating their unedited testimonies, even though they produced many hours of material. Ross and Funari state that distilling people's recordings into "short bites" makes it challenging to communicate "nuance" (2017, p. 287) and allow individuals who are recording themselves or being recorded opportunities to develop their thoughts. They add that truncated narratives make it harder for others to "go on a journey" with people whose lives and experiences are being examined (2017, p. 287). Rather than being able to "witness and move through their thinking process" (2017, p. 287) in a natural way, Ross and Funari claim that edited narratives force people to come to unnatural conclusions. I was also concerned that edited recordings might not reflect the processual, collaborative, dialogic, and sustained ways in which my interlocutors produced their testimonies. I also questioned whether a series of recordings that offered glimpses into the participants' experiences would allow users to come away with a clear enough understanding of what my collaborators have been through and were trying to communicate.

I am also mindful that Ross and Funari argue that in order to create a work of art that has the potential to inform and move people, there must be an "authorial, edited presence, a voice, a concept" (2017, p. 287). They add that, as with the digital memorial we produced, there can be more than one creative producer, but there must be a clear "structure and point of view" (2017, p. 287) that connects all of the media in a particular project. Therefore, in spite of my instinct to share the participants' testimonies in an unedited manner, I realized that we needed to trim their recordings into shorter, listenable nuggets if we were going to hold users' attention.

I asked my collaborators if they were willing to select five of their recordings and to identify five to seven minutes of content from each of these. My interlocutors were supportive of this suggestion, so and I sent them transcripts of their recordings and asked them to highlight the content they wanted to share through the project. My collaborators made careful decisions about what they wanted to share, and I edited their audio recordings according to their instructions.

Erica Lehrer and Cynthia Milton describe curation as an act of "care-taking" (2011, p. 3). They add that to "care for" (2011, p. 3) the past is to make something of it, to place and order it in a meaningful way in the present rather than to abandon it. The edited excerpts of the participants' recordings highlight a range of themes, experiences, emotions, and facets of their respective connections to Michael. In Lehrer and Milton's words, the participants "create a social

space for a shared experience of looking, listening, and talking, creating alternative relationships and publics, for constructive meaning making and action taking" (2011, p. 3). Ross and Funari insist that it is vital for media producers to provide enough context and framing in order to allow people to properly understand the background and relevance of a project (2017, p. 285- 287). I do this by including a brief text-based description of the project as part of the memorial. I will also provide a link to an electronic version of this thesis, although I recognize that few users will read it in full.

When it comes to disseminating the participants' personal narratives, I am mindful, as Lehrer and Milton insist, that there are a number of risks. The authors warn that in spite of our intentions, the project and my interlocutors' narratives may not be received as we hope they will be. They argue that in effect, we have produced and are sharing what Deborah Britzman calls "difficult knowledge" (1988). Lisa Taylor, Unwalli Sollange, and Marie-Jolie Rwigema explain that the term refers to information that is primarily "kept outside the bounds of the 'thinkable'" and is "introduced into the conscious attention of a learner" (2015, p. 107). They add that disseminating information of this nature can challenge people to consider their roles in "historical systems of violence and inequity" (2015, p. 107). According to Taylor, Sollange, and Rwigema, this can make listeners uneasy, as it challenges the way some think of themselves as "good" people. They insist that untangling ourselves from systems that oppress others "takes time and self-observation," but it is not a process that everyone welcomes (Taylor, Sollange, and Rwigema, 2015, p. 107).

Lehrer and Milton argue that our society is increasingly exposed to "images of human suffering" (2011, p. 1). They claim that sharing even more images, and I would add audio recordings, is becoming less and less effective in terms of shaping public and decision makers' attitudes. They argue that disseminating "violent, tragic, gruesome, horrific, and painful," material can lead to even greater "exclusions" and reinforce pre-existing "divisions and prejudices" (2011, p. 7). As much as we hope the project can help inform people about the impacts of the opioid crisis, Lehrer and Milton caution that the participants' "suffering" may not "ennoble, but may embitter, isolate and agitate" (2011, p. 7).

#### **Sharing authority**

The task of selecting which audio clips would be published as part of the digital memorial led me to change my mind about shared authority. As I mention in Chapter 1, I

initially envisioned maintaining control over the editing process and the determining the final content of the project. However, after seeing that my collaborators were clearly invested in our work together, I concluded that it no longer felt appropriate or comfortable to me to hold the balance of power. The participants had spoken openly about their grief and their relationships with Michael, and I knew I would not feel comfortable deciding which parts of their testimonies to disseminate and which to withhold. Who was I to say what they should share with the world and what they should keep to themselves? I told them that my position had changed. It felt freeing to release the need to control every minutia of the project and to share authority in a more comprehensive way. I hoped my decision would allow my collaborators to feel even more comfortable taking part in the project. I believe my decision to work more collaboratively encouraged the participants to share even more deeply with me in their recordings and our conversations.

I felt emboldened in my decision by reading how former NFB documentary director Fernand Dansereau came to similar conclusions. His 1962 film, *A Saint-Henri le cinq septembre*, or *September 5 at St. Henri*, as it is translated in English, focuses on inhabitants of one of the poorest parts of Montreal. When the film was released, its primary subjects were upset with the way they had been represented. They reported that they felt humiliated and chose to move their children to a different school (Moore, 1987, p. 59). By reflecting on their responses, Dansereau recalls that he felt "deep remorse . . . in spite of our undeniable goodwill" (1968, p. 34). He claims that he regretted his decision to not allow his subjects to be involved in the editing process (1968, p. 4). Their negative feelings prompted him to adopt more participatory and democratic strategies on his next film, and to invite people whose lives were documented to censor its content. His film, *Saint-Jérôme* (NFB & Dansereau, 1968), focuses on the impacts of technology on a small community in the Laurentians. Dansereau recalls that in allowing people who were filmed to determine the final content of the project, he was prioritizing "human relations" (1968, p. 35). He adds: "I told myself that it was placing the same confidence in them that I was asking them to place in me" (1968, p. 35).

Dansereau not only invited subjects to be involved in the editing process. He and his fellow producers shared rushes from the documentary with people who had been filmed, asked for their feedback, and made changes based on what they communicated. As a result of the progressive way that the film was made and the trust its producers developed with community members, when it was released, it was positively received by local residents (Dansereau, 1968, p.

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36). The methods that Dansereau and his NFB colleagues employed in this film influenced strategies that other directors experimented with as part of the CFC/SN. His innovative collaborations changed the status quo that had been ingrained by the Film Board's previous commissioner, John Grierson.<sup>32</sup>

In spite of my willingness to share authority with my collaborators, in some ways I was not prepared for what working in more participatory ways would entail. I discovered that establishing consensus about a number of issues took considerably longer than I anticipated. For example, Carina and I exchanged emails over more than three months about which image of Michael we would place at the start of the memorial. The photograph was important, because it would set the tone for the whole project. We discussed several options, including photos of Michael teaching meditation and one of Michael standing in a snow-covered field with his back to the camera. Carina also shared images of orange flowers, and another of rocks on a beach. I struggled to see how these would fit with the project. As much as I appreciated Carina's feedback, facing a deadline to complete the memorial and thesis, I began to find the back-andforth discussion challenging. I also felt the project risked not moving forward, because it was taking us a lot longer than I expected to make decisions. I wrote the following field notes:

I remind myself that this is a participatory project. I would not want to create a digital memorial for Michael on my own without involving my collaborators. It just requires patience. Every researcher and media producers who works in collaborative ways knows this. I resolve to stay open to their feedback, but I will have to let them know that I need to meet deadlines with the project and that our debates over which images to use and more cannot go on for much longer. The challenges that I am feeling are normal in light of how the project is designed. I am grateful that the process of recording my collaborators' testimonies with them was very efficient. Even curating and editing their

<sup>&</sup>lt;sup>32</sup> During Grierson's tenure at the NFB from 1939 to 1945, filmmakers were given the authority to make virtually all creative and aesthetic choices, even while producing films about social issues. Documentary makers rarely consulted with participants about how they were represented and seldom invited them to watch films before they were released. Beginning in 1966 with the creation of CFC/SN, a group of filmmakers at the NFB, inspired by Low, altered their way of working and began to treat participants as genuine collaborators whose input was a vital. These strategies also led to the recognition at the NFB that the process of participatory filmmaking and influencing social change were more important than the final products that were produced. George Stoney, who was an American and executive director of the CFC/SN from 1966 to 1970, argued: "Both film and video were crafted to make things happen, not the event itself" (qtd. in Wiesner, 1992, p. 81).

testimonies was relatively straight-forward. Designing and assembling the digital memorial is not, and I have to accept that. In spite of the challenges, I trust that the process is appropriate and that it will benefit them, myself as a researcher, and that the final digital memorial that we publish will appeal to viewers and communicate the messages to decision makers in the way that we have intended. (June 28, 2018)

The second challenge that I want to address also relates to the participatory nature of the project. As noted previously, as we began to consider publishing the memorial online, my collaborators and I decided to first share their recordings with a small number of people who knew Michael. Our intention was to invite these individuals to share feedback with us in order to get a sense of how the testimonies were received. In spite of our agreement on the method, I made a decision on my own to ask the test listeners to contribute their own recordings and memories of Michael. In doing so, I began to take the project in a new direction without consulting my collaborators. After Carina expressed her dissatisfaction with my choice, I asked the listeners to only respond to the original participants' recordings and not share their own memories of Michael. I reflected on my impulse to open up the project to greater involvement from the listeners, and I realized that at the time, I was feeling bogged down by the numerous exchanges I was having with my collaborators about the project's interface. Feeling the pressure of trying to complete the memorial and thesis, I thought that inviting others to take part might make the production process easier, because it was feeling stalled in some respects. I realized that I cut a corner and made a mistake. Carina's instruction that she wanted to keep the project "intimate" (personal communication, July 6, 2018) alerted me to the need to work more closely with her and the other participants and stay true to our original plans.

## **Other challenges**

As noted previously, the busy nature of the participants' lives and the fact that they were grieving meant that they produced fewer recordings than we originally discussed. It also took longer than I anticipated for them to curate their testimonies and either choose or create images for the memorial. Andréa reported that she found it emotionally taxing to listen to her recordings (personal communication, April 23, 2018). I understood and imagined what it must have been like for her reliving memories of Michael while she was about to get married and welcoming

family to her home. I did not want to add any pressure or cause Andréa to experience added emotional stress. I indicated to her that I was happy to discuss her choices with her when she was ready and had more time.

Roughly six months into the project, Carina informed me that she needed to put the "brakes" (personal communication, April 12, 2018) on our work together. She told me there was a risk of a lawsuit because certain individuals were trying to control the narrative about Michael's death. She said that she would need to vet the other participants' recordings before they could be published online. Carina apologized for the "slow down" (personal communication, April 12, 2018). When I learned of this, I communicated to Carina that there was a lot at stake for me and that I needed to complete the project. At the same time, I did not want to expose her or my other collaborators or myself to a possible lawsuit. After we spoke about it, Carina signaled that we could carry on as we had been working. We have not spoken about it since, and it did not interrupt our work together. I also do not think any of the content of the participants' testimonies or the memorial itself could be reasonably viewed as a violation of Michael's privacy or a defamation of his character. In this sense, I do not have any concerns about disseminating the project online.

I had hoped to wrap up production by July 2018, but by September of the same year, the participants were still deciding which images to use in the memorial. After nearly a year working together, it felt understandable to me that their energies had started to dissipate. In the end, we made choices that I believe we are all satisfied with, and I am grateful for their commitment that allowed us to finish the project.

## Conclusion

In this chapter, I provided details about interactivity, my decision to use Klynt as a platform, and some of the affordances and limitations of interactivity in participatory projects. I examined how interactivity is used in *The Quipu Project* (Lerner & Court, 2015), *Blood Sugar* (Daniel, 2010), and 86 ½ Years (Usborne, 2017), and how I used these projects as models to archive and disseminate my collaborators' audio testimonies. I presented highlights of how I conceptualized the digital project, sought my collaborators' feedback, and how we created it together. I examined how the participants curated their testimonies, how I view this material as "difficult knowledge," and explored some of the implications of this for the project. I highlighted how we shared authority, and how my position on the matter changed. I discussed how briefly

considered making the memorial an open-space project, recognized that this was not in line with the participants' vision, and chose not to do so. Lastly, I reflected on a small number of challenges that I faced while working with the participants and discussed how we addressed these.

In the following chapter, I explore how my collaborators and I plan to disseminate the project with publics, journalism organizations, and decision makers. I outline that the digital memorial will not stay on the internet forever, and address the fact that many other countermemorials have also been designed to be impermanent. I present highlights of how the participants view their own recordings, as well as how two external listeners responded to their narratives. I share brief concluding thoughts about the testimonies, and the chapter ends with brief suggestions for areas for future research.

# CHAPTER 6 CODA

## Introduction

In this chapter, I explore how the project was created as a temporary memorial and explain how I find it appropriate that it will not remain on the internet indefinitely. I then examine some of the ethical and political considerations of the project. The chapter then features a discussion of how I plan to share the digital memorial with various publics. I finish the chapter by briefly exploring areas for future research.

### Impermanence

The digital memorial that we have created will not remain online forever. I suspect that in three to five years, technology will likely evolve to the point that it is no longer feasible to keep it on the internet. A number of interactive producers have faced this situation with their projects. For example, Cross and his collaborators spent years creating *Homeless Nation* (Aung-Thwin, Cross, & Gaylor, 2003). Today, the audio-visual content that they curated is no longer available to the public, because technology has rapidly changed. Many of Cizek's projects are also not available online to all users, because much of her work requires an updated version of the interactive program, Flash (personal communication, Nov. 2, 2018).

Financial costs also frequently impact scholars' and media producers' abilities to keep interactive projects online. The fees for hosting the digital memorial for Michael for three years are reasonable, and it is always possible to pay to keep it online longer. Larger and more elaborate projects can cost significant amounts, and this is not always sustainable over long periods of time.<sup>33</sup>

Many scholars and designers have deliberately created counter-memorials in ways that ensure they will not permanently exist. The memorial that Kirsten McAllister built with community members in order to commemorate Japanese-Canadians who were interned in New Denver, B.C. during World War II will ultimately be consumed by the environment it is situated

<sup>&</sup>lt;sup>33</sup> The producers of the interactive documentary, *Hollow* (www.hollowdocumentary.com) paid \$750 US per month in server fees. http://ijnet.org/en/blog/hollow-creators-offer-tips-making-interactive-documentaries

in. The cedar and pine used to rebuild internment shacks, paper displays, wool clothing, shoes, and even a garden, will all vanish (McAllister, 2011, p. 119-120). McAllister insists: "It is the perishing, the decay, that is potent." She adds: "Although the NIMCS attempts to preserve the potency of the past in eternity, the remains give it a form in which it can fade, dissipate, and transform" (2011, p. 122).

*Losing Michael* will be online long enough to reach various publics, and then it will vanish. The temporary nature of the digital memorial is appropriate and reflective of what Michael and other Buddhist instructors teach, namely that everything, including our human lives, are impermanent.

## Ethical considerations and compensation

I learned in my previous research projects collaborating with individuals who use heroin that working with members of vulnerable populations requires a significant amount of forethought and planning. Not only is this needed in order to ensure that collaborators are not harmed by taking part in research projects, but it is required by university research ethics boards (REBs). When it came time to planning this project, it was not any different. The REBs at Concordia University and Kwantlen Polytechnic University were very stringent, as expected, and asked that I submit evidence in order to illustrate that I would do everything possible to ensure the participants did not experience elevated levels of emotional or psychological distress, or were negatively impacted in other ways. In what follows, I present highlights of four major areas that I considered and discussed with my collaborators prior to the start of our work together and throughout our collaboration. Doing so enabled me to gain their trust and satisfied the REBs' requests. I also discuss the compensation that was provided to my collaborators for taking part in the project and briefly refer to the role that Buddhist ethics played a role in the study.

## **Transparency**

It was important for me to clearly inform the participants about my goals for the project. Early on, I indicated that I was interested in assisting them in producing testimonies about their connections to Michael and about their experiences with grief. I stated that the purpose of doing so was be to challenge dominant and stigmatizing narratives about the opioid crisis. By amplifying their voices and experiences, I explained that I hoped that we could create greater awareness about the linkages between mental health and drug-related deaths and the need for more early intervention programs for people with mental illness.

I informed the participants that I was interested in adapting Greenspan's research methods, which I briefly outlined for them, and working with them over a sustained period to create a digital memorial about Michael. Beyond that, I told them that I was open to collaborating with them in unconventional ways, and I was interested in hearing how they wanted to proceed. We established that they would record audio testimonies on their own and in conversations with me, and take part in semi-regular dialogue and email exchanges about their recordings. I then outlined the research methods and relevant information in an informed consent form and distributed it to the participants them for them to further consider and sign. It was important to establish the parameters of the project at an early stage. They needed to be clearly informed about my expectations of them, including how often I hoped they would contribute testimonies and communicate with me. I also let them know what my role in the project would entail. I indicated that if new information presented itself, I would inform them of this.

### **Risks and benefits**

It was clear from the outset that by inviting the participants to share information about their lives, about Michael, and their grief, that they could potentially experience a number of risks. These included psychological discomfort and emotional distress. As indicated previously, I originally approached Carina and the two other participants just weeks after Michael had died. It was a sensitive time for them, and I did not want to cause them any additional harm. I asked if they had sufficient support systems in place, and they all assured me that they did. I had the sense that in spite of the very real challenges that Michael's passing had created for them, they were not completely isolated. They told me that they were regularly speaking with counsellors and members of their meditation community who were friends with Michael.

I felt obligated to inform the participants about other risks before they agreed to work with me on the project. I let them know that there was a possibility that people who heard their testimonies and learned about their stories through the digital memorial could potentially judge them. I indicated that people with sinister intentions could potentially repurpose the audio-visual content that they would create and that we would disseminate online. I also informed them that our conversations, either by phone, Skype, or email, could possibly be monitored by outside parties. Lastly, I noted that if they happened to use drugs and speak about this in the context of

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the project, it could possibly negatively impact their housing or employment situations, and lead to social stigma.

When it came to potential benefits, I let the participants know that the project would give them an opportunity to produce and share in-depth stories, express emotions, and memorialize Michael. I indicated that I planned to support them in these processes, and that this might allow them to feel listened to in a compassionate way. I added that by creating and disseminating their testimonies, they may gain a sense of helping publics and elected officials learn more about the impacts of fatal overdoses for decedents' loved ones, and as noted previously, about the need for more early intervention programs for individuals with mental health challenges.

## **Privacy and confidentiality**

The project involved sharing personal information in recorded testimonies and images. I assured the participants that the data they shared with me would be stored in a safe place and that no one else would have access to it. I informed them that I would keep all their media content on a password-protected hard drive that I would lock in a cabinet in my home office. I indicated that I would keep the data for five years, and that I would then permanently delete it.

I let my collaborators know they had the option of using pseudonyms and photographs that did not reveal their faces in order to help disguise their identities. They all said these measures were not necessary and that they were willing to be identified in the digital memorial and in this thesis. Even if we had taken steps to conceal their identities, people who knew them and Michael would have been able to figure out who they are.

### Rights to participate, say no, or withdraw

I stated to the participants that they were not obligated to take part in the project. I also let them know that they could withdraw from our collaboration at any time. However, given that I needed to finish the project in order to complete my PhD in a timely manner, I asked that if they chose not to be involved in the work after initially agreeing to participate, that they let me know within the first month of our collaboration. I wanted to be sure that they had enough time to determine if the project was the right match for them, and that if they opted to withdraw, I would have sufficient time to make other arrangements, either by developing a new project or inviting other individuals to take part. I asked that if they withdrew from the project after our first month working together that they grant me permission to use their data on condition that I attempt to conceal their identities. If this situation were to arise, I agreed to not publish any images in which the participants could be recognized, to use actors to recreate their voices or modify their voices electronically, and to refer to them in the memorial and thesis by pseudonyms. As noted above, I recognized that some people would likely still be able to identify them, but I needed assurance that I would be able to work with the content they created in order to complete the project.

### **Compensation**

I informed my collaborators that they would each receive \$666 in compensation for taking part in the project. I hoped that this would help make up for some of the income they would likely lose by devoting significant amounts of time to the study. Also, I had \$2,000 in funding for participant honoraria, so dividing this amount in three felt appropriate.

### **Buddhist ethics**

In addition to what I have outlined above, Buddhist values guided my interactions with the participants. Although I did not refer to Buddhist ethics in my communications with the REBs, I felt that because Michael taught meditation, and my three interlocutors and I practice medication and mindfulness, it was appropriate to consider and apply these principles. Above all, it was important for me to draw on two primary and inter-related concepts from Buddhism, namely to "intend no harm" and to "intend to be of benefit" (Stocking, 2009, p. 292). S. Holly Stocking argues that ancient Buddhist ethics are relevant for contemporary media producers. She claims that adhering to these principles means that media makers must strive to not cause harm. They can do this by refraining from engaging in divisive or hurtful speech, stealing other people's data, creating stories that create risks for people, using abusive language, using sex to obtain information, and engaging in gossip. In order for media producers to be of benefit, she asserts they must attempt to decrease judgment and bias through their work, reduce others' suffering, provide comfort, and create content that can be used to find solutions to problems (Stocking, 2009, p. 292).

### **Political considerations**

Throughout this thesis, I have discussed how people who have experienced fatal overdoses have been rendered unworthy, exotified, and silenced. My central motivation in creating the digital memorial about Michael has been to collaboratively produce nuanced and humanizing testimonies about him that resist stigmatizing narratives. There are, however, political implications of working with individuals such as my collaborators who are connected to well-known figures such as Michael. Although I view Michael as part of a wider group of people who use drugs and have experienced overdoses who have been consistently cast by media organizations and decision makers as social outcasts, he is relatively unique in the sense that his death was widely reported on by multiple journalism organizations.

In producing this project, I have had to consider whether I am inadvertently sending a message to publics and decision makers that Michael is worthy of being memorialized because of his reputation as a spiritual teacher, his socio-economic status, physical appearance, intelligence, or charisma. I respect Michael and was intrigued to learn more about him and communicate this information to others, however, I do not see him as worthier of being mourned or commemorated than any other individual who has lost their life to an overdose. Working with my collaborators in order to pay tribute to Michael was simply a match for me, because of my interest in meditation and yoga, and because of my personal experiences related to my mother. Given that many people who have overdosed suffered from mental illness and experienced significant difficulties, I believe that it would have been beneficial and for me to focus on others who have died in the midst of this health crisis. I recognize that this doctoral project and digital memorial could be interpreted as a replication of the power relations and biases that have characterized much of the visual reporting on the opioid crisis for years. In focusing on Michael, my intention was, in part, to help reveal that in spite of many photographers' tendencies to produce images of people who are homeless and poor, many individuals outside of communities such as the DTES and from all sectors of society are being affected by opioid-related overdoses.

I also considered how in the aftermath of episodes of mass violence, politicians have seized upon the sadness, grief, and mourning of their citizens for their own gain. For example, according to David Simpson, in the wake of the attacks of September 11<sup>th</sup>, many Americans, who were experiencing "grief, sorrow, [and] shock" felt "the urge, in the immediate aftermath . . . to make a statement, to testify, to register a response, to initiate some sort of commemoration" (2006, p. 13). Politicians in the U.S. used the tragedy in order to shore up a

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sense of nationness, patriotism, and to fuel their military campaigns in Iraq and beyond in the Middle East. Simpson argues: "Mourning and melancholia have both been made secondary to the initiation of new states of emergency" (2006, p. 4). Sven Czek adds that the Bush administration "blatantly manipulated" the tragedy and "national traumatization" in order to "serve as an excuse for the invasion of Iraq" (2011, p. 10).

Even at Ground Zero in Manhattan where the World Trade Center towers had fallen, groups of citizens rallied together in order to fend off the politicization and commercialization of commemorative sites (Donofrio, 2010, p. 151). The website of the organization Take Back the Memorial states that it is critical to commemorate those who died in the events of September 11<sup>th</sup> without allowing the tragedy to be co-opted by powerful actors with their own agendas. It adds "it is so important that any memorial or museum built at the site remain dedicated exclusively to telling the story of 9/11, free from external interpretation or context" (Shurbet, 2008).

Although the political manipulation of grief that took place in the aftermath of the attacks of September 11<sup>th</sup> may be an extreme example, I believe there is value in reflecting on these events. Doing so allowed me to reconfirm to myself that people who have experienced loss and are grieving are vulnerable, and that as a researcher, it was critical that I honoured and respected my interlocutors' visions for the project, and that I did not use it or them to advance a personal political agenda, even though our collaboration was a central part of my doctoral work.

### **Dissemination strategies**

#### Media outreach and scholarly production

The goal of the project was to resist dominant narratives about the opioid crisis, people who use drugs, and individuals who have experienced fatal overdoses, and to include the participants' voices and experiences in the wider discussion about the systemic causes and the personal and social consequences of fatal overdoses. As noted previously, I will contact a number of journalism organizations to inform them about the project and ask if they would like to interview my collaborators and me. I was able to generate considerable local, national, and international media attention with my previous research-creation projects with people who use heroin in this way.<sup>34</sup> I will also create awareness about the project through social media and by

<sup>&</sup>lt;sup>34</sup> My research study involving documentary photography, photo-elicitation and interactive technology aimed at humanizing vulnerable individuals who use heroin in Vancouver received considerable local, national, and international attention. I conducted interviews with several radio stations, including CKNW, Radio-Canada, and

informing my network of academics, journalists, harm reduction researchers, advocates, and others. I also plan to produce scholarly papers or a book about the project, and deliver lectures at academic conferences.

## Informing elected officials

By sharing their personal testimonies about their memories, their connections to Michael, as well as their grief, my collaborators wanted to help alter the nature of public discourse and memory about the opioid crisis and those who have experienced fatal overdoses. They were also interested in delivering a message to decision makers about the need for more early intervention programs for people with mental illness. I will contact authorities at the local, provincial, and federal levels who are responsible for health care and harm reduction in order to let them know about the project and our concerns.

### Conclusion

The overarching purpose of this project, as outlined in this thesis, was to humanize Michael as an individual who suffered from mental illness. In doing so, along with my collaborators, I hoped to resist dominant narratives about people who use drugs and experience fatal overdoses. I also wanted to highlight the links between mental health and the opioid crisis and create awareness about the need for more early intervention programs for vulnerable people.

My interlocutors' testimonies reveal that Michael suffered for years as a result of bipolar disorder without telling many people about it. Although he faced the challenges of a mental illness, Michael accomplished many things in his life. He became a successful and widely respected meditation and yoga instructor, and was a prolific writer and communicator. He was also a loving and cherished partner, father, and friend. Media reports about Michael's passing could never fully describe the impact he had while he was alive and how strongly his death has been felt by those who knew and cared about him.

Newspapers, magazines, and online publications contain countless images of people who use illicit substances and individuals who have experienced overdoses in public spaces. Too often, these individuals are othered by the media and represented as social outcasts. Dominant

WOSU Public Radio, an NPR affiliate station in Ohio. The project was also covered by *The Vancouver Sun, The National Post*, BBC3, and *Artsy*.

narratives fail to convey that people from all sectors of society are dying from opioid overdoses. This project and the participants' nuanced narratives about their connections to Michael, their memories of him, and their grieving processes reveal the magnitude of their losses. They also point to how vulnerable people need access to more harm reduction programs and health care services in order to stay safe and protected.

By building upon Greenspan's method, my collaborators and I developed close connections with each other that allowed them to share in meaningful ways and produce original knowledge about the opioid crisis. There were minor hurdles along the way that I have highlighted in this thesis. Given the sensitive nature of the content that my collaborators and I explored together and the challenges they faced in the aftermath of Michael's passing, I am grateful for my interlocutors' commitment to the project.

Adopting an autoethnographic approach and exploring some of my experiences related to my mother's bipolar disorder, lengthy disappearance, and death, enabled me to connect with my interlocutors in a profound way. Although I only shared a few details of my personal life with my collaborators, I believe that our common experiences caring about someone one with a mental illness allowed us to work closely together in order to produce their testimonies. Exploring my own memories and grief as I reflected on my interlocutors' narratives also enabled me to gain insights and clarity about my personal experiences.

The project also allowed me to learn more about research that is conducted by universitybased scholars and community members, which, as outlined in the thesis, High, Miller, and Little describe as "going public" (2017). Exploring the concept of shared authority allowed me to reflect on and contextualize the approach that I adopted with my interlocutors.

I have begun planning further participatory research projects with people who use drugs and are in recovery from substance use disorder, including members of immigrant communities in the Boston area. In these projects and others, I will continue to experiment with different approaches to collaborative photography, multimedia production, testimony, and interactive work. As a result of the insights that I have gained through this doctoral project, I will begin future projects with the understanding that participatory methods can be beneficial for participants, researchers, and wider publics.

## Areas for potential future research

This project examined how the participants' testimonies disrupt dominant narratives about the opioid crisis and individuals who have died from causes connected to drug use. It would be helpful to explore how other members of the public respond to these recordings. Do they think the testimonies communicate nuanced information that challenges assumptions that are conveyed through the media about people who use drugs and experience fatal overdoses? Does the project communicate insights about connections between mental health, drug use, and fatal drug-related overdoses?

It would also be interesting to ask more listeners about how they received the participants' recordings. Did the testimonies hold their attention? Do people have a sense that excerpts of the testimonies that the participants shared through the digital memorial offer clear, cohesive, and compelling narratives? Do they feel that the project could benefit by including additional information? It could also be helpful to conduct focus group interviews with people to learn how they engaged with the interactive elements of the digital memorial. Does it allow users to develop a sense of agency? Which content did they choose to engage with and why? How do users compare the experience of engaging with the interactive project with consuming text-based or audio-visual material about the opioid crisis that is presented in a linear manner? Does the interactive nature of the project support our goal of humanizing Michael?

Further research could also explore whether memorials for individuals who have experienced fatal overdoses that allow greater numbers of citizens to contribute to them are able to reach decision makers and influence policy. For example, the digital memorial highlighted in Chapter 2, which is published by the National Safety Commission, could be an interesting case study. I am not aware of any studies that have examined this or other open space and interactive memorials focused on the opioid crisis.

When it comes to photojournalists, documentary photographers, and even nonprofessionals with smartphone cameras, I think it will take a long time for these individuals to consider the impact of how they produce images of people who use drugs and experience overdoses. Many photojournalists face deadlines and work in an industry that is not known for being overly critical of its methods. My aspiration, however, is that this project can contribute to conversations about media practice and invite photographers, scholar-producers, and other media makers, to experiment with alternative, collaborative, and humanizing ways of documenting the opioid crisis and those whose lives are affected by it.

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