Louise Snowball, Room #237

An exhibition of installation and mixed media

by

Ellen Snowball

A thesis exhibition presented to OCAD University in partial fulfillment of the requirements for the degree of Master of Fine Arts in the Interdisciplinary Arts, Media and Design program.

"The Great Hall", 100 McCaul St, 2nd floor

April 11 - 17th

Toronto, Ontario, Canada, April 2019

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I authorize OCAD University to lend this thesis to other institutions or individuals for the purpose of scholarly research.

I understand that my thesis may be made electronically available to the public.

I further authorize OCAD University to reproduce this thesis by photocopying or by other means, in total or in part, at the request of other institutions or individuals for the purpose of scholarly research.

Signature _____

Ellen Snowball, OCAD University, *Louise Snowball, Room #237*,
Master of Fine Art, Interdisciplinary Arts, Media and Design, 2019

Abstract

Louise Snowball, Room #237, is an interactive, multi-sensory installation that draws upon my personal experiences of observing my mother's decline from dementia. In 2012 my mother, Louise Snowball, was diagnosed with Alzheimer's disease, and subsequently admitted to a long-term care facility until her death. During this time, I documented my mother's experiences through photography to express the emotional impact it had on me. Using auto-ethnographic and research creation methodologies, I began to explore how a three-dimensional practice could build upon this work. My research into *The Medical Gaze* (Foucault) discusses how the gaze can position the viewer within the installation space. The theory of *The Abject* (Kristeva) is used to describe how medical environments can cause abjection, and writing on *Embodiment* (Merleau-Ponty) and research into interactivity in game design and mechanics (Clement) will illustrate how a viewer's physical interaction with an installation space has the potential to unlock new knowledge.

Dedicated to my mother, ***Louise Snowball*** (4/02/2017).

List of Figures

Introduction

In 2012, my mother was diagnosed with early onset-Alzheimer's disease when she was 61-years-old. The neurologist informed our family that her life expectancy was only four years. As falls, broken bones, and bruises became commonplace, I began taking photographs and videos of my mother as a way to cope with the emotional and mental strain. Over the years, my mother's symptoms increasingly worsened, and my family admitted her to a long-term care facility in 2015. During my visits, I began to contemplate how her diagnosis and environment might have negatively impacted her sense of identity.

When I entered OCAD University in 2017, it became my objective to share my personal experiences with my mother's dementia. During this time, my research led me to discover Michel Foucault's concept of *The Medical Gaze*, Julia Kristeva's theory of *The Abject*, and Maurice Merleau-Ponty's thoughts on *Embodiment*, which became important to me as I explored new ways of communicating my personal experiences through my work. Diverging from my background in photography, I began using mixed media installation and autoethnographic methodologies to create an adaptation of my mother's room in her long-term care facility. After a little over a year of iterative exploration, I have completed a final body of installation-based work, entitled *Louise Snowball, Room #237.*

My Master's thesis paper describes the context of my research into dementia, including my observations of my mother's experiences with the disease, and unpacks how this close connection has informed my research questions, practice, and objectives. I address the formal qualities of the final body of work, and explain how they are linked to my conceptual and theoretical research. In addition, I expand upon the research creation and autoethnographic methodologies that I have used to create my final work, examining how my practice has shifted from photography to installation-based work. I also postulate how my art-based research may contribute to an expanded awareness of the potential ways that long-term care facilities shape our understanding of people with dementia.

My Story

When my mother was first diagnosed with early onset Alzheimer's disease in 2012, I was a 21-year-old undergraduate student studying photography at OCAD University. As a young woman living at home, I was witness to my mother's decline due to her disease. Her ability to communicate began to diminish over time and soon I could no longer have conversations with her. As her symptoms worsened, she began to fall and hurt herself; broken bones and bruises became commonplace, which often required me to call an ambulance. When my father was away, I took care of my mother by cooking and feeding her meals, helping her go to the bathroom, bathing her, and changing her clothes. Our roles were now reversed, and it was my turn to take care of the woman who once took care of me. While watching my mother go through this difficult period, I felt a profound sense of guilt for not having had a closer relationship with her. In my opinion, my mother had always suffered from undiagnosed mental and emotional problems and this, over the years, often resulted in arguments between us. As a homeschooled child, I often had to cope with the abuse of her outbursts and manipulative behaviours; these made me feel confused and isolated for most of my life.

Coping with this trauma was no easy feat; I didn't feel as if I had anyone to turn to, and I couldn't fill the void of sadness I felt growing inside of me. After my mother's diagnosis, I suffered from severe anxiety and depression and started using drugs and alcohol as a way to distance myself from the immense pain I was feeling. I knew that I would never have the chance to fully repair my relationship with my mother. At a time when I needed a mother the most, she could not be there for me, and I knew that one day she would not be there to watch me grow up. I was angry that I couldn't fix this situation and resentful that my mother's illness was not something that my family could ever really talk about. It was as if an unspoken curse had fallen onto us that we all, in our own ways, tried our best to ignore. Through the encouragement of my cohort and a few professors, I began taking portraits and videos of my mother as a way to cope with the emotional impact of my mother's dementia. Photography and videography allowed me to document my everyday reality and expose the raw nature of what it was like to watch someone you love suffer from dementia. I wanted to show how beautiful my mother was, and that despite her

declining health, she still had autonomy. It was at that time that I discovered that my art practice gave me the opportunity to communicate my perspective.

Although I always received my mother's consent to take these photographs, I received criticism from family members who deemed my work to be objectifying and exploitative. These accusations hurt me deeply. Although I did not agree with them, I began to question my role in taking photographs and videos of my mother by contemplating how the gaze could operate against someone suffering from dementia. My interest in the gaze continued to develop when my mother was admitted to a long-term care facility in 2015. I was shocked at how medicalized her new "home" was, and I could not believe that she was being treated as just another "sick" person who needed to be locked away from society. My feelings were amplified by the knowledge that she was fearful and resistant to being admitted into this kind of environment. Through my own experiences at my mother's long-term care facility, I became critical of medical institutions because I felt that my mother was being positioned as an object of her disease, rather than as an autonomous subject with will, integrity, and knowledge. I was so profoundly affected by this experience that I often had difficulty visiting my mother, and afterward, I would usually require a few sick days off from work to emotionally and mentally recover.

On January 29th, 2017, my family was informed that my mother was no longer eating food or drinking fluids. A week later, on February 4th, at 12am, she passed away from starvation due to dysphagia. When I was accepted into OCAD University's Interdisciplinary Master's in Art, Media, and Design Program in March of 2017, I decided that it was important for me to share my experience of my mother's illness through my art practice. It is my hope that my thesis project, *Louise Snowball, Room #237*, can provide insight into issues surrounding dementia as well as create awareness for people residing in long-term care facilities.

Research Questions

My Master's thesis employs interactive installation to explore four primary research questions related to issues surrounding dementia. These questions have been informed by my theoretical research into the work of

Michel Foucault, Julia Kristeva, Maurice Merleau-Ponty, and Ryan Clement, as well as my own personal experiences of my mother's dementia. The following is a list of these questions and their theoretical underpinnings:

1. According to Michel Foucault's concept of the *The Medical Gaze*, medical practitioners and nurses often separate their patient's body from that of their identity[1]. How does the gaze position those with dementia as objects of their disease, rather than autonomous subjects? How can the gaze be utilized within installation in order to confront this objectification?

2. In *Powers of Horror: An Essay on Abjection*, Julia Kristeva uses the example of a corpse to describe that the abject, at its very core, is a state of rejecting what is other to oneself [2]. This experience of the abject evokes feelings of disgust, horror, and even fascination. How might the abject cause dementia patients to be positioned as other? How might installation serve to question those positions?

3. Maurice Merleau-Ponty argues in *Phenomenology of Perception*, that moving and experiencing do not merely establish the experience of being, but are also modes of being within themselves [3]. How can we renegotiate ideas of embodiment, identity, and selfhood, through installation? Can an installation create a phenomenological experience for a viewer if they are invited to physically interact with it?

4. In Ryan Clement's thesis *Playing the Story: The Emergence of Narrative through the Interaction between Players, Game Mechanics, and Participatory Fan Communities*, game mechanics are described as the rules-based systems that act as the "tools of interaction, allowing the player to act within the artificial environment of the game space and influence the outcome of his or her game" [4]. Clement argues that game

---

[1] Foucault, Michel. "The Birth of the Clinic: An Archaeology of Medical Perspective" New York: Vintage Book Publishing, (1973): 08, 34.
[2] Kristeva, Julia. "Approaching Abjection" *Powers of Horror: An Essay on Abjection*, New York: Columbia University Press, (1982): 3.
[3] Merleau-Ponty, M. "Phenomenology of Perception" London: Routledge, (2002): 166 - 170.
[4] Clement, Ryan. "Playing the Story: The Emergence of Narrative through the Interaction between Players, Game Mechanics, and Participatory Fan Communities." www,uwpsace.uwaterloo.ca
https://uwspace.uwaterloo.ca/bitstream/handle/10012/12681/Clement_Ryan.pdf (Accessed February 8th, 2019), 6 - 7.

mechanics can produce emergent narratives as part of the interaction between players and gameplay [5].

How might interactive installation employ game mechanics to produce emergent narratives?

<center>Michel Foucault's *The Medical Gaze*</center>

In his book, *The Birth of the Clinic*, Michel Foucault offers the reader a detailed account of the origins of Western pathological medicine by analyzing the scientific climates, both historically and culturally, of the eighteenth century in Europe and North America. He identifies a synthesis between two discursive practices of medicine after the Enlightenment: the anatomization [6] of corpses and the nosology [7] of clinical practice. Foucault notes that it is during this synthesis that *The Medical Gaze* emerged as way for medical practitioners to gather "knowledge of the living, [so that] ambiguous disease could be aligned with the white visibility of the dead" [8]. Foucault suggests that the medical practice of dissecting corpses allowed for the gaze to reveal disease as residing *inside* the body, which correspond to symptoms visible on the *surface* of the body[9].

Foucault contends that the gaze is problematic, because it inherently objectifies the patient by viewing their body as separate from their identity [10]. He states, "In the clinic, the patient is the accident of his disease, the transitory object that it happens to have seized upon." [11]. The patient then becomes the object of the medical practitioners gaze, who observes the patient's symptoms, classifies them as belonging to a *healthy* patient or a *sick* patient, and then offers a diagnosis and prescribes a treatment. The gaze renders the patient "an external fact; the medical reading must take him into account only to place him in parenthesis." [12].

The isolation a patient experiences when their personhood is rendered invisible reminds me of when my mother refused to attend her follow-up appointment with her neurologist. After months of enduring test after test, it seemed that my mother became embarrassed and fearful about her illness. She spent most of her time hidden away in her room, watching television. My father went to her appointment for her, and while discussing the results of the

---

[5] Clement, 1.

[6] to cut apart (an animal or plant) to show or examine the position, structure, and relation of the parts; display the anatomy of; dissect. https://www.dictionary.com/browse/anatomize (Accessed March 3rd, 2019)

[7] the systematic classification of diseases. https://www.dictionary.com/browse/nosology (Accessed March 3rd, 2019)

[8] Foucault, 126.

[9] Foucault, 129.

[10] Foucault. 135.

[11] Foucault. 59.

[12] Foucault. 8.

tests, the neurologist abruptly informed him that my mother's life expectancy was only four years. Apparently, there were no viable treatment options available, and the disease would only become more and more aggressive. There was little support and very few resources that were offered by my mother's doctor. After the technicians conducted MRI, CT, and PET scan images of her brain, the results were objectively gazed upon by the neurologist and categorized as abnormal. Much like Foucault's description of *The Medical Gaze*, my mother's identity was not taken into account. During this time, it was clear to me that my mother felt fearful of her diagnosis, perhaps because this process of objectification would position her as powerless over her disease. It didn't matter who my mother was, or how she felt about her illness. To the doctor, she was just another host to a disease that needed diagnosing. Perhaps if the neurologist had taken a more holistic, inclusive and compassionate approach to diagnosing patients, by considering and supporting the personhood of people with dementia, my mother might not have been so fearful about her medical appointments.

<div align="center">

The Medical Gaze & Difference

</div>

While Foucault's concept of *The Medical Gaze* is important to understanding how power is negotiated between the patient and the medical practitioner, it does not account for how differences in race, gender, culture, or class may affect this relationship. For example, in *The Medical Gaze: Medical Models, Power, and Women's Health*, Deborah Findlay argues that modern science and biomedicine are patriarchal in origin [13]. Findlay asserts that biomedicine in the 1950s played an important role in constructing ideas about women's femininity and biology that still prevail today [14]. She states that during this time obstetric and gynecological interpretations of women's bodies, "often assumed normality to be the culture of reproduction and motherhood characteristic of white, middle-class nuclear families" [15]. Although biomedicine has historically been characterized by objectivity, neutrality, and rationality, Findlay postulates that both science and medicine *always* contain social assumptions and value

---

[13] Findlay, Deborah. "The Medical Gaze: Medical Models, Power, and Women's Health" Atlantis, Vol. 18, Nos. 1 & 2, 1992 - 1993, 108.
[14] Findlay, 109.
[15] Findlay, 109.

judgements of researchers or practitioners [16]. Clearly, assumptions of "social normality" have influenced medical

classifications and categories that seek to identify abnormal symptomologies, and diagnose patients [17].

According to the article *Intersectionality in Clinical Medicine: The Need for a Conceptual Framework* by

Yolonda Wilson et al., introducing the concept of intersectionality to clinical medicine requires practitioners to think

about "the ways in which categories like race, gender, sexuality, and class interact with one another and shape our

sense of self and of how we interact in the world" [18]. Wilson states that structural and institutional forces that

discriminate against individuals can significantly affect their health and welfare and further perpetuate inequality by

race, gender, sexuality, culture, and class [19]. For example, she notes that black women in particular are

disadvantaged due to differences in race and gender, and have shown higher rates of infant mortality, low birth rate,

hypertension, and excess weight gain in comparison to white women [20]. Wilson asserts that adopting an

intersectional approach to healthcare can further assist in recognizing how institutional practices have advantaged

some while disadvantaging others [21]. With this in mind, it is clear that subsequent texts to Foucault's *The Birth of the*

Clinic have shown that *The Medical Gaze* can operate differently on those who are not the white, male,

heteronormative subject. It is important to consider that *The Medical Gaze* is not a homogenous experience that is

the same for everyone, but a multifaceted encounter that is characterized by complex power relations and manifests

differently for each individual.

<div align="center">The Institution</div>

Foucault describes medical institutions, such as clinics, hospitals, and long-term care facilities, as spaces

that serve to perpetuate the gaze and exert power over individuals [22]. For example, the hospital is discussed as a

homogeneous environment where a "generalized presence of doctors whose intersecting gazes form a network and

---

[16] Findlay, 108.

[17] Findlay, 108.

[18] Wilson, Yolonda, et al. "Intersectionality in Clinical Medicine: The Need for a Conceptual Framework" *The American Journal of Bioethics*, 19(2), (2019), 9.

[19] Wilson et al., 9 - 10.

[20] Wilson et al., 9 - 10.

[21] Wilson et al., 11, 9.

[22] Foucault, 13.

exercise at every point in space, and at every moment in time, a constant, mobile, differentiated supervision." [23]. As Foucault explains, clinical environments arose as spaces where medical practitioners could sustain a constant observational gaze upon their patient, and eliminate any possible variables in diagnosing and treating their patient.

Before my mother was admitted to a long-term care facility, she had expressed to me that she was fearful of going into a "home". She said she didn't want to leave her family, and she felt that people in charge of her care wouldn't know who she truly was. When she was finally admitted to a long-term care facility, she would constantly beg for me to take her away. One time I discovered her sitting in her wheelchair, in a separate room. As I bent down to ask her if she was okay, she managed to mumble, "Get. Me. Out. Of. Here!". Similar to what Foucault describes, my mother's care facility was very homogeneous. The fluorescent lights, putrid smells, and deafening alarms, were all reminiscent of a hospital environment. Every room looked identical; clinical and unwelcoming. My mother's life became controlled by the surveilling gaze of the nursing staff. Many of the residents, including my mother, sat in the hallways for hours, where caretakers could observe them closely. Mealtimes and bathroom visits were tightly scheduled, and residents were seldom allowed to move on their own. Doors were never allowed to be closed, except for the entrances and exits, which remained locked until a password was entered. At this time, it became clear to me that my mother's new "home" was not a home at all, but a prison.

Julia Kristeva's *The Abject*

In Kristeva's *Powers of Horror: An Essay on Abjection*, the abject is a stage understood as a fundamental experience of human existence; it is neither object nor subject, but a state of rejecting what is other to oneself [24]. Abjection is described by Kristeva as a response to the loss of distinction between subject and object, or self and other, resulting in horror and disgust. Kristeva states, "the jettisoned object, is radically excluded and draws me toward the place where meaning collapses." [25]. The abject is embodied through what is jettisoned, or rejected. It is excluded from oneself, such as sour milk, excrement, vomit, or waste. According to Kristeva, we re-enter into this

---

[23] Foucault, 32.
[24] Kristeva, 4.
[25] Kristeva, 2.

meaningless state when we encounter abjection because we cannot make sense of this conflict. The process of abjection can evoke both feelings of horror and disgust, as well as jouissance, or fascination with the abject [26].

During my mother's time at the long-term care facility, the sights, smells, and sounds of the environment often caused me to enter into a state of abjection. The first few times I visited my mother, I noticed that most of the surroundings appeared to be unkempt and outdated. The floors looked sterile and plastic and the baby-blue walls were outfitted with large handrails and sanitizing dispensers. The facility resembled a clinic or a hospital, rather than a home. I felt anxious under the fluorescent lights and the smell of urine and stale air made me feel nauseous. The ventilation was very poor and none of the windows opened. An unanswered phone rang constantly, causing me to feel agitated. A television blared loudly and alarms would often be triggered; my mother's floor was incredibly noisy at all times. One man, who often sat in the hallways, yelled "Help me!" for hours on end, yet was completely ignored by staff. While observing the nurses interacting with my mother, I noticed that they were often distant, authoritarian, and cold. When they were friendly, they spoke with a condescending tone that reminded me of the way some parents speak to their children. Every time I visited, I couldn't imagine spending more than a few hours in my mother's long-term care facility and I usually felt an overwhelming sense of relief when it was time to leave.

The Corpse

As Noëlle McAfee explains in *Julia Kristeva*, a situation which sets off abjection is the presence of a corpse. The abjection occurs while trying to negotiate the dead body. The corpse, who was once alive, is no longer a subject but an object that has been claimed by death [27]. As McAfee argues, "The corpse does not represent something, as a symbol might; it is a direct 'infection' of my own living." [28]. The 'infection' of the living that McAfee describes can also be applied to sick, elderly bodies that require full-time nursing care, such as dementia patients.

Boundaries become blurred when the dementia patient "infects" the life of the living. As discussed by Trudy Rudge and Dave Holmes in *Abjectly Boundless: Boundaries, Bodies, and Health Work*, the defective mind of

---

[26] Kristeva, 9.
[27] McAfee, Noëlle. "Abjection" *Julia Kristeva*. New York & London: Routledge Publications, 2004: 44 - 51
[28] McAfee, 47.

the "demented" is manifested through disruptive behaviours that threaten the caregiver by "embodying a disruption of the clear system of order through which human beings maintain and secure their integrity and autonomy." [29]. Because the patient signifies the unbreakable interrelationship between life and death, the subjective 'I' of the caregiver or medical practitioner becomes destabilized. In turn, the caregiver or medical practitioner's own sense of subjectivity is challenged because it is contingent on a clear system of order that differentiates 'I' from 'other' [30].

Much like a corpse, individuals that suffer from dementia disturb the symbolic order, because it can be difficult to negotiate them as subject or object. Because people living with dementia are unable to always exert control over their bodies or minds, their integrity as autonomous beings is often called into question. Caregivers, medical practitioners, and even family members, who are exposed to disruptive behaviours, bodily fluids, bodily orifices, and physical signs of degeneration, may experience abjection, and thus encounter an unconscious urge to protect themselves from being violated by the other [31].

As my mother's disease became worse, her fingers began to contort in unnatural directions and her teeth appeared as if they were rotting. At mealtimes, she would choke on her food, often spitting everything up. At one point, a nurse had to suction out some food and a thick, mucousy saliva that had become stuck in the back of her throat. My mother had lost a significant amount of weight, and I became distressed when I could see her bones protruding from underneath her skin. Toward the end of her life, she wore adult diapers and sometimes I could smell urine or feces when I was around her. The other residents at the facility also caused a great deal of abjection for me. Residents would often yell or scream in the hallways; the sight of their distraught faces made me feel horrible for them. I wondered where their families were, and if my mother ever felt distressed like them. Each time I visited my mother, I had horrible anxiety. I often experienced panic attacks as I watched my mother's body slowly deteriorate in disbelief and horror. Regardless of this disturbing experience, I still sought out opportunities to connect with my mother. I visited her whenever I felt emotionally and mentally prepared to do so. We shared tender moments by cuddling together in her hospital bed, holding hands, or watching television together. Despite her symptoms, my mother was still present and able to communicate with me through our shared experience of touch.

---

[29] Rudge, Trudy, and Dave, Holmes. "Subjectivity and Embodiment: Acknowledging Abjection in Nursing" and "Encountering the Other: Nursing, Dementia Care, and the Self" *Abjectly Boundless*: *Boundaries, Bodies and Health Work.* 2016: 273
[30] Rudge, Holmes, 274.
[31] Rudge, Holmes, 276.

Maurice Merleau-Ponty's Embodiment.

According to Maurice Merleau-Ponty, in his book *Phenomenology of Perception*, experiencing, moving, and thinking are not activities that are exclusively related to cognition, but are actually activities of a bodily consciousness [32]. While the Cartesian mind-body split conceives of the body as merely another physical object in the world, and the mind functioning as an isolated, subjective self, Merleau-Ponty views the body as a form of consciousness that is not separated from the mind [33]. He challenges the Cartesian model of the split between mind and body through his notion of embodiment or bodily consciousness [34].

One way that Merleau-Ponty demonstrates this stance is through his discussion of motor skills as practical knowledge. Merleau-Ponty makes a distinction between two types of knowledge; knowing *that* something is the case (episodic or propositional memory) and knowing *how* to do something (procedural memory). Contemporary neuroimaging reveals that episodic and procedural memory systems function independently in different processing areas of the brain, and procedural memory endures even as episodic memory is lost [35]. You may forget the circumstances when you learned to ride a bicycle, for example, but your ability to ride a bike – the embodied memory that this requires - remains functional and intact. Propositional knowledge, or knowing *that*, is constituted by beliefs, where the subject forms conceptual beliefs and endorses them as true. Knowing *how*, on the other hand, consists of being able to do something when the subject is in the right environment [36]. This is most evident in Merleau-Ponty's analysis of motor skills. Merleau-Ponty claims that, at times, the subject is able to experience their actions, such as the use of motor skills, as occurring without the guidance of intentional thought. He argues that instead of thought, it is the subject's perceived environment that initiates and controls their behaviour [37].

Motor Skills as Embodiment

---

[32] Merleau-Ponty, 166

[33] Romdenh-Romluc, Komarine. "Routledge Philosophy Guidebook to Merleau-Ponty and Phenomenology of Perception." London, Routledge (2010): 62.

[34] Romdenh-Romluc, 86.

[35] "Declarative (Explicit) Memory & Procedural (Implicit) Memory" human-memory.net http://www.human-memory.net/types_declarative.html (Accessed March 15th, 2019); Judith Doyle, "Warmware: Mnemonic Art and Design Research", Mobile Nation, Riverside Press, M. Ladly and P. Beesley, eds. 2008, p. 199.

[36] Romdenh-Romluc, 82.

[37] Merleau-Ponty, 166.

According to Merleau-Ponty, recognizing the opportunity to engage in an activity results from the subject immediately perceiving a suitable environment in which to exercise their skill - rather than objectively judging the situation [38]. For example, when it was dinnertime in my household, my mother would often stretch out her hands to reach the food that was on her plate. Once she had grasped a piece of food, she would slowly move her hand up to her mouth. It could be argued that these motor skills were triggered by the sight and smells of the meal that was served to her, adding to the "dinnertime" environment. A parallel can be drawn between Merleau-Ponty's thoughts on motor skills, and Sara Ahmed's concept of *Orientation*. Ahmed describes orientation as a phenomenon that occurs when bodies seem to be oriented toward or against certain objects or spaces [39]. She argues that to be oriented toward, or against, these objects or spaces includes an emotional intentionality [40]. Our emotional intentionality directs us toward certain things and we become affected by "what" we come into contact with. Ahmed, much like Merleau-Ponty, seeks to understand the spatiality of bodies toward particular directions, and how these directions can create new knowledge [41].

<div align="center">Affectivity as Embodiment</div>

In Stephan Millet's paper *Self and Embodiment: A Bio-Phenomenological Approach to Dementia*, Merleau-Ponty's idea of *embodiment* is described as the body's embeddedness in the lived-world - or a directly experienced world. Millet discusses that this "being-in-the-world" includes affective or emotional responses, and he asserts that people with dementia can experience these responses when faced with triggering stimuli. He states, "Affective or emotional responses – signs of happiness, sadness, frustration, anger and the like – are indicators of an interior life, the extent of which may not be determinable using cognitive criteria alone." [42].

Similarly, Shiloh Whitney's dissertation paper, *Affect and Difference in the Philosophy of Merleau-Ponty*, considers how Merleau-Ponty describes affective or emotional responses as the body becoming possessed by

---

[38] Romdenh-Romluc, 85.

[39] Sara, Ahmed. "Queer Phenomenology: Orientations, Objects, Others." Durham: Duke University Press, 2006. 1 - 2.

[40] Ahmed, 2.

[41] Ahmed, 2.

[42] Millet, Stephan, "Self and Embodiment: A Bio-Phenomenological Approach to Dementia" Sage Publications, 2011, http://dem.sagepub.com/content/early/2011/06/14/1471301211409374 (Accessed Jan 20th, 2019).

meaning, without any need for direct representation [43]. Merleau-Ponty states: "the expression cannot be distinguished from the thing expressed" [44], the meanings of which are evoked rather than represented, or as Whitney puts it "incarnated instead of signified" [45]. Just like Merleau-Ponty's discussion of motor skills, affective, or emotional responses, can possess the body with meaning and become part of an embodied experience, and this experience isn't necessarily linked to cognition.

For Merleau-Ponty, perception, knowledge, and consciousness, are not the mere registering of objective features of the world, but a bodily response to one's environment. Merleau-Ponty argues that practical knowledge of one's body, such as motor skills and affective or emotional responses, are a form of self-knowledge, or bodily consciousness. Motor skills and affectivity or emotionality, then, are not merely mechanical responses to external stimuli or movements exclusively ruled by thought, but rather, are embodied exercises that can unlock new knowledge about the world. When observing my mother at her long-term care facility, I often noticed that she would try to get up and move out of her wheelchair. Even when she could not vocalize her needs, she would push on handles and straighten her legs, propping herself forward until she was standing on the foot straps of her wheelchair. It was evident to me that she wanted to get up and move her limbs, but the nurses would not allow her to do so because she was prone to falling. She would often gaze or point in the direction of something that caught her attention, and sometimes she would stick her contorted fingers in her mouth or tug at her clothes. At the time, I used to try to interpret these physical movements the best I could by asking her questions about how she was feeling and if she needed anything. I realized that these attempts would not work, so I began engaging her in other ways. After my mother stopped verbalizing, I discovered that she was still able to respond to my physical touch, and that her physical movements became a way in which she could still communicate. I would warm my hands under a blanket, and clasp my hands around hers; she would turn and glance at me with big, watery eyes. Informed by Merleau-Ponty's thoughts on embodiment, I believe that my mother's body still held consciousness, and this consciousness could be accessed through physical movement, touch, and affectivity. By touching her hands, for

---

[43] Whitney, Shiloh, "Affect and Difference in the Philosophy of Merleau-Ponty" McGill University, 2013: http://digitool.library.mcgill.ca/webclient/StreamGate?folder_id=0&dvs=1548021436204~204 (Accessed Jan 20th., 2019).
[44] Merleau-Ponty, 175.
[45] Whitney, 96.

example, I believe that this physical intimacy allowed my mother to become aware of my presence and this simple gesture became our shared knowledge of love.

Installation Work

The Gaze

Foucault's analysis of the gaze has informed my approach to the creation of a multi-sensory installation that is an adaptation of my mother's long-term care facility. I employ strategies to activate a viewer's gaze throughout my installation as a means to build a viewer's self-awareness of their shifting position within the work. It is important to my thesis work that viewers experience the feeling of watching/observing as well as being surveilled or observed. To accomplish this positioning, the construction of the installation space involves a large picture window and multiple peepholes that encourage external viewers to peer into and observe the viewers that are inside. The shifting positioning of viewers refers to power structures involved in exercising or receiving the gaze. For example, the external viewers may assume the point-of-view of the intrusive gaze of the medical practitioner or nurse, while the viewers inside the installation may assume the point-of-view the objectified patient.

Presence, Positioning & The Gaze

I evoke my mother's presence within the installation through the inclusion of personal video and audio clips, texts and projections. In addition to creating a window and peep holes for viewers to look into and out of the work, I have included a medical privacy curtain to activate the gaze through the positioning of the viewer. The fabric of the curtain has been laser-cut with passages from my mother's emails to me, which address her feelings and thoughts on her diagnosis. In order to reveal the text on the curtain, viewers will be provided with flashlights that illuminate the text within the dimly lit installation space, casting shadows onto the adjacent wall, revealing out-of-focus sentences that will only be readable by observers who are standing on the opposite side of the curtain. Since I am allowing two people inside the installation space at a time, viewers will have to depend on each other to illuminate the curtain while they explore the shadows on the opposite wall. This positioning of viewers within the

installation space evokes the dependency that people with dementia often experience with their caregivers within medical institutions, and the blurry words operate as a metaphor for the symptomologies that people with dementia often experience.

Control & The Gaze

I have configured an old television to play brief, almost subliminal clips from a video of my mother and me in her nursing home that I recorded just before her death. Short clips from this video will play every three to five minutes and function as interruptions of a longer video that I recorded of my family's house, where my mother spent most of her time after her diagnosis. The juxtapositions created by these quick interruptions suggest the inability to leave the institutional setting, and a desire to return home to family.

In addition, the disruptive scene, which does not seem to belong on the television, represents a private, hidden moment between mother and daughter. By revealing this intimate footage incrementally, I am engaging viewers in a voyeuristic position by controlling how and when these narrative "clues" are revealed to them. It is important that I exercise some control of my viewer's experience within the installation because I want to evoke how long-term care facilities control the bodies of people with dementia. I am exerting this sense of control through the intentional timing of each audio clip, video clip, or projection, which together evoke how caregivers tightly schedule mealtimes, bathroom visits, and activities, for those with dementia.

The Abject

I reference Julia Kristeva's notion of *abjection* within my installation in order to demonstrate that institutional environments, such as long-term care facilities, can perpetuate the othering of people with dementia. Many of the abject elements in my installation have been inspired by my experiences of the sights, sounds, and objects that I have encountered in my mother's long-term care facility.

I employ audio as one method of triggering abject responses in viewers, in order to cause them to experience anxiety. For example, I have configured a telephone to ring intermittently, along with flashing red LED lights. The loud repetition of the ringing phone is reminiscent of my time spent in my mother's long-term care

facility, where the noisy atmosphere was cluttered with alarms and unanswered telephones. The ringing of the telephone, and the flashing red LED lights, are intended to create a sense of agitation within viewers, and it is my intention that this feeling of anxiety will prompt them to interact with the object by picking up the telephone receiver. Because a ringing phone is a familiar object, I anticipate that it is likely to elicit an interactive response from a viewer.

The Abject & Death

The medical hospital bed, as well as the privacy curtain, are both objects that I have collected from long-term care facilities, and these items retain the liminal presence of their original environments. Many of these objects have retained their musty, hospital-like smell, and this authenticity brings an abject quality to the installation.

All of the objects in the installation have been painted white. White, a shade I associate with death, is intended to enhance the clinical homogeneity of the installation and brings the space into a "dream-like" or "other-worldly" dimension, where time has ceased to exist. I have subtly stained each object with coffee grounds in order to reference disease or bodily fluids. In this way, I am suggesting an association with impurity and contamination, which may cause viewers to experience an overall feeling of abjection from the space.

Presence & The Abject

I further explore feelings of abjection by implying my mother's ghostly presence within the work. For example, I employ an audio track of my mother's laboured breathing, which I recorded before her death. The audio has been edited to repeat on a loop, at a very low volume level, and the speaker playing this recording is hidden underneath a pillow on the hospital bed. This audio makes reference to my mother's struggle to breathe during the final days of her life, and the viewer may feel as though she is still present within the space. A television, located directly across from the bed, plays a video loop that appears to change channels repeatedly as if it were controlled by an unseen viewer. These ghostly elements are intended to trigger an affective response in viewers by suggesting the presence of the patient (in this case my mother) whose body is no longer present within the room.

In addition to the sound of laboured breathing and the constant changing of the channels on the television set, I have created a timed, animated projection of my mother walking across the back wall of the installation room.

The animation depicts her in silhouette as a white, shadowy shape, slowly staggering through the room with her walker. Viewers become aware of this animated projection when an audio cue of the squeaking wheel of her walker can be heard as if it is coming from "off-screen". After its appearance, the animation quickly fades into darkness only to reappear seconds later on the opposite side of the wall. The life-sized, silhouetted animation, is strongly suggestive of my mother's presence because it is rotoscoped, or traced, directly from a video that I shot of her walking in her long-term care facility.

<div align="center">

Phenomenology & Embodiment - Clues & Interactivity

</div>

Inspired by Merleau-Ponty, I intend to evoke a phenomenological experience in the installation space that requires embodied responses from the viewer. I do this by creating a multi-sensory experience that viewers can participate with through physical gestures and affective or emotional responses. The reason for this is to challenge the notion that people with dementia lose their "knowledge" or "identity" when they can no longer speak, or can no longer obviously recognize loved ones.

I have intentionally planted visual and aural "clues" within the installation space that often require the physical interaction of the viewer in order to uncover their meaning. This method is used to suggest that it is possible to unlock new knowledge through embodied responses. For example, before entering the installation, I will be present to instruct viewers to take flashlights to observe items within the dark installation space. I will also inform viewers that they are encouraged to physically interact with objects. The medical privacy curtain, which has been laser cut with messages, further encourages viewers to explore their physical surroundings. While illuminating the fabric with the flashlight, viewers become aware that their interaction with the curtain dictates the clarity of the shadowy words that are projected onto the adjacent wall. If a viewer is standing too far from the curtain, the words will become blurry. If the viewer advances to a closer position, the words will come into focus and become legible. In this way, elements in the installation activate the physical position of the viewer so that they may uncover meaning in the work.

Since my mother's death, I have had highly unsettling dreams about saving my mother from fire, drowning, or suicide. I have hidden small booklets throughout the installation that contain watercolor and ink drawings of these dreams. The drawings are accompanied with handwritten passages that describe the context of the dreams. The

covers of the booklets have been bent open, so that a section of the drawing can peek through. The viewer is intended to discover these booklets and become tempted to pick them up and read them. It is my hope that by informing viewers that they can touch objects, they will feel inclined to do so. Similarly, the urgency of the ringing telephone beckons the viewer to answer; when they do, an audio track of my mother and I having a conversation about her thoughts and feelings on her diagnosis with dementia will automatically begin to play. By coming into contact with these items, the viewer begins to uncover narrative clues about the work, thus uncovering new knowledge through embodied responses.

Timing, Prompts & Interactivity

In addition to providing the viewer with objects that reveal clues, I have strategically timed each audio, video and projection element to reveal itself or play at certain moments. These timed elements, such as the ringing phone or the squeaking wheel of the walker, function as prompts that beckon the viewer to interact with the objects or to direct their attention to certain areas of the installation and thus reveal the clues.

As David Rokeby discusses in *Transforming Mirrors: Control and Subjectivity in Interactive Media*, a correct route is not always important to interactive spaces; the emphasis, rather, can be placed on a viewer's discovery and exploration of the environment [46]. According to Rokeby, relinquishing an amount of control can give the impression that the viewer has much more freedom than they actually do [47]. As a result, the viewer is free to establish their own personal reading of the work by following their own path of interest, rather than being told specifically where to go and what to do.

Although I am adopting this model, I am also choreographing each element to appear based on how much time I imagine a viewer will spend moving throughout the space. This tactic is informed by my experience of objectively watching individuals explore the installation while it was set up for testing. In doing this, I am providing some prompts that will assist the viewer in navigating the installation, as well as mimicking my personal experiences in the chaotic environments of long-term care facilities, where the sounds of loud telephones, alarms,

---

[46] Rokeby, David. "*Transforming Mirrors: Control and Subjectivity in Interactive Media*" DavidRokeby.com, *http://www.davidrokeby.com/mirrorsnavig.html* (Accessed Jan 2nd, 2019).

[47] Rokeby, David. "*Transforming Mirrors: Control and Subjectivity in Interactive Media*" DavidRokeby.com, *http://www.davidrokeby.com/mirrorsnavig.html* (Accessed Jan 2nd, 2019)

and yelling residents often overlapped. Viewers are given the freedom to piece together narrative insights at their own pace and comfort level and are encouraged to form their own subjective opinion about what the overarching narrative is.

Construction

For my thesis exhibition, I have had the privilege of acquiring sponsorship from *The Alzheimer Society of Toronto*, a non-profit organization offering support, information and education to people with dementia and their families and caregivers. I have also secured sponsorship from *The Rekai Centres*, a long-term care facility located in downtown Toronto. Through the generosity of these two establishments, I have had the opportunity to construct a large room (8'Hx12'Wx16'L), in the Great Hall of 100 McCaul Street. The physical structure is made out of multiple 4'x 8' plywood "flats", insulation, and soundproofing blankets. The room is designed to be modular, allowing for the drywall to be disassembled and reassembled easily, making it possible to store the structure for future exhibitions [Fig 9 & 10]. Inspired by Samuel Roy-Boi's installation *Ghetto*, from 2006, where the artist has constructed an architectural "module" with a large window that overlooks a bed and Janet Cardiff & George Bures Miller's *Opera For Small Room*, where the artists have constructed a room with a window, my structure includes a window, peep holes and door openings to invite observation and allow viewers to enter and exit the work.

Two at a Time: Gaming & Interactivity

I was also inspired by the concept of an escape room, which is a physical adventure game where participants are required to solve puzzles or riddles using clues, hints, or strategies, in order to "escape". I started watching a popular Netflix series called *Hellevator*, a horror game show where contestants have to solve puzzles in a haunted warehouse to win prize money. Many of the episodes used actors, lighting and design techniques, and audio to direct participants through a constructed environment. I became fascinated with the idea of controlling the viewer by constructing a physical space where narrative "clues" could be found. This type of interactivity was evident in video games I was playing at the time, such as *Alien, P.T., Fallout*, *Bioshock, Far Cry*, *Last of Us*, *Red Dead Redemption*, and *Uncharted*, all of which use a first or third-person perspective to encourage players to solve

puzzles, collect items, and complete quests in order to survive or escape. The virtual environment of these games prompted me, the player, to interact with objects to uncover narrative elements and create meaning within the game.

During this time, I would often play video games with my partner, such as *A Way Out*, *Gauntlet*, *Diablo*, and *Star Wars Battlefront II*, but I grew frustrated by how few multiplayer, "couch co-op" games were available for Playstation 4. Because of this, I started thinking about how interactivity could become an intimate, shared experience between two people within an installation space. Serendipitously, when I purchased flashlights for my installation, they came in a pack of two, so I began testing them out by only allowing two people in the room at a time. I began to realize that by restricting how many people enter the installation, I was referencing my experiences of visiting my mother where the two of us would connect in her room at the long-term care facility.

Game Mechanics & Physical Space

In Brenda Brathwaite and Ian Schreiber's *Challenges For Game Designers*, game mechanics are described as the rules-based systems involved in a game [48]. Game mechanics can be understood as systems that act as the tools that players use to interact with a game, such as objects, avatars, experience levels, or player turns [49]. These tools can cause certain things to happen within the game. For example, if a player's avatar has interacted with an object during gameplay, it may cause a particular response from the mechanics of a game. According to Ryan Clement's thesis *Playing the Story: The Emergence of Narrative through the Interaction between Players, Game Mechanics, and Participatory Fan Communities*, game mechanics allow for players to "act within the artificial environment of the game space and influence the outcome of his or her game." [50]. Game mechanics can control exactly what information is exposed to the player at any given time, functioning as a rule-based system that users must abide by in order to play the game. I employ my own version of game mechanics, where there are rules and information that viewers must hear before they enter the installation space of *Louise Snowball, Room #237*. For example, only two viewers are allowed inside the installation at a time. Each person is given a flashlight and informed, by me, that the installation is interactive and that they are welcome to touch objects. They are also instructed to enter the installation

---

[48] Brathwaite, Brenda. Schreiber, Ian. "Challenges for Game Designers" Boston: Course Technology (2009), 28.
[49] Clement, 19.
[50] Clement, 6 - 7.

through the entrance door and exit through another that is located at the back of the room. By stating these rules, the viewers are made aware of the mechanics of the installation, allowing them to know how to navigate space, as well as encouraging them to interact with objects through physical touch.

Game mechanics can also produce narrative elements within a game by using objects that players can interact with. Clement discusses that video games utilize elements of *story*, *narrative*, and *emergent narrative*. Clement points out that *story* in video games relate to the way that plot elements are specifically organized or ordered [51]. In contrast, he defines *narrative* as the unfolding of events from which we make meaning through our interpretive experience. He notes that *narrative* has far a greater flexibility to be non-linear than *story.* While *story* usually remains as a consistent "reality" of the game, *narratives* have the ability to convey new information [52]. *Emergent narrative*, on the other hand, is defined by Clement as a narrative that emerges from the interaction between players and game mechanics, often through the experience of playing the game [53].

When thinking about the physical design and construction of the room, I was inspired by how video games could utilize non-linear, emergent narratives through the interaction of players and objects in order to create a meaningful experience. The construction of the room is designed as a space that can be physically navigated and interacted with as a way to provide narrative insight into my experiences with my mother's dementia. Viewers can become aware of the installation space, and their physical positioning, through the use of the flashlights, proximity to windows and peepholes, as well as their interaction with objects.

As with game mechanics, these elements have been intentionally placed within the installation environment to encourage viewers to uncover emergent narratives within the work. Objects, such as the telephone, projection, and television, have been strategically timed to "turn on" at different intervals, acting as prompts for the viewer to interact with them. A viewer's physical position and level of interaction with objects may impact their experience of these narrative "clues". Similarly to video games, if a viewer chooses not to answer the ringing of the telephone, they will miss out on the narrative provided by that mechanic. Although there are no strict rules regarding the

---

[51] Clement, 19.
[52] Clement, 19.
[53] Clement, 20.

sequence in which these objects should be discovered, they have been configured with intention as a way for viewers to navigate the space, making them part of the "game mechanics" of the installation.

Methodologies & Methods

Auto-ethnography: Gathering Emotions

During the process of creating my installation, I have used auto-ethnographic approaches as a way to incorporate my personal narrative and experiences into the work. I accomplished this through collecting and interacting with audio recordings, videos, and personal objects that belonged to my mother, as well as recording my thoughts, feelings, and dreams in a journal. I used my mother's notebooks, journals, jewelry, photographs, as well as video footage and audio recordings, as a way to explore my emotions and reflect upon my experiences. In the process of doing so, I began to study the personal significance that these objects, videos, and recordings held for me. I realize that these items have become sacred to me, and that the act of touching, watching, and listening to them is not only a way for me to grieve, but also a way of reconnecting with my mother. While I naturally gravitated toward auto-ethnographic methodologies, I was also inspired by the prolific artist Louise Bourgeois, who, since her death, is well known for her vast collection of personal journals and poems, which she wrote from the ages of 14 to 91[54]. Bourgeois was also an avid collector of personal objects and items, and never threw anything out [55]. Similarly to Bourgeois, I have collected personal objects and items, and used journaling and reflection as a means to cope with my personal experiences and trauma.

In my video work *In Pieces (2018),* I began to document my reactions to reading my mother's notebook and journal entries, as a way to become aware of my emotions. Similarly, in a two-channel video entitled *Hands of Mother and Daughter (2018)* I recreated video footage of my mother by placing myself in similar physical positions and environments [Fig 1]. These methods and projects allowed me to identify the emotional impact my mother's

---

[54] "Louise Bourgeois's Powerful, Confessional Poems Will Now Be Published for the First Time- and You Can Read One Here" news.artnet.com https://news.artnet.com/art-world/louise-bourgeois-writing-glenstone-1268621 (Accessed February 8th, 2019)
[55] "A Look Inside the Louise Bourgeois House, Just How She Left it" nytimes.com https://www.nytimes.com/2016/01/24/arts/design/a-look-inside-louise-bourgeoiss-home-just-how-she-left-it.html (Accessed February 8th, 2019)

death had on me, and assisted me in the process of utilizing these items within my art practice to share a narrative insight into my experience.

Research Creation: Uncovering The Past

While revisiting my photographs and videography, I began to gather as much feedback from my cohort and professors as I could. I shared images and videos from a series entitled *Don't Cry, It's Not That Bad (2016)*, produced when my mother was still residing in a long-term care facility. In one video, titled the same, I documented my mother in her long-term care facility room; unable to move or speak, my mother lay, propped up, in her bed, gazing at the camera [Fig 2].

The video depicts my mother lying motionless on her bed with nothing but her foot slowly rocking back and forth. This footage was projected large-scale on a white wall and played continuously on a loop for hours. The repetitive ringing of an unanswered telephone, broken narratives of a loud television show and the periodic voices of nurses tending to other patients who can be heard in the background. My mother appeared to have become an unmoving object, cast away and ignored in a clinical bedroom while the chaos of the external world surrounded her.

When I spoke about this work during a critique, I realized that I was still resentful that my mother had been locked away in a facility and that she was, in my opinion, treated like an object of her disease. I started to question how people with dementia are positioned in a medical environment, and if this positioning might affect their sense of identity or autonomy. Ignited by this frustration, I searched for literature that addressed some of the issues surrounding long-term care facilities and dementia. That's when I discovered the research of Renée L. Beard, a medical sociologist who has written about the sociocultural dynamics of Alzheimer's disease in relation to biomedical models of care, such as long-term care facilities. In her article, *In Their Voices: Identity Preservation and Experiences of Alzheimer's Disease,* Beard states: "The dichotomy between mind and body, implicit in the very ethos of modern biomedicine [56], influences societal perceptions of aging and elevates the status of 'mind' over that

---

[56] the application of the natural sciences, especially the biological and physiological sciences, to clinical medicine. https://www.dictionary.com/browse/biomedicine (Accessed March 14th, 2019)

of the 'body.'" [57]. Inspired by Beards critical stance on biomedicine, I began using research creation methodologies to explore how I could make work that offered a similar perspective.

Process

From 2D to 3D

As my engagement with my mother's illness and my personal experiences of her dementia care developed, I realized that it was important to me to expand my work beyond the use of photography, which I had relied on as a way to document my experiences with my mother. Although my experience with my mother was very subjective, photography, for me, was a way in which I felt that I could immortalize the fleeting moments I shared with my mother in an objective, two-dimensional way. However, after my mother had passed away, I wanted to diverge from this practice because I no longer felt that it adequately represented my past or present experiences. I was no longer recording my everyday realities but revisiting my experiences through memory, reflection, or dreams and this subjective, personal narrative, called for a more layered practice. When I began contemplating the pain and trauma of my mother's illness, it occurred to me that not many people know what it is like to witness a loved one reside within a long-term care facility. I decided that I wanted to provide the viewer with the opportunity to encounter the same sights, smells, and noises that had caused me so much distress at my mother's "home", while also finding ways to share my experiences with my mother's dementia.

At this time, I began reading Julia Kristeva's *Approaching Abjection* in my critical theory class. The theory of *abjection* related to my personal experiences in the clinical environment of my mother's long term care facility, and I used this theory to inform my transition into installation work. For my first attempt at installation, I decided that I would simply replicate the environment of a clinical waiting room. Relying on my experiences and memories, I searched online for waiting room chairs, and scoured Value Village for tacky, broken, and stained, furniture and decorations that were reminiscent of my own experiences in clinical settings. I painted the walls of the critique room

---

[57] Beard, Renée. "In Their Voices: Identity Preservation and Experiences of Alzheimer's Disease" Journal of Aging Studies 18, no. 4 (2004): 416.

a salmon-pink color in order to evoke an outdated feeling [Fig. 3]. I incorporated an atmospheric audio recording of

my mother's long-term care facility; the ambient buzz of fluorescent lights, ringing of telephones and distant voices,

seemed to produce anxiety in the viewer that linked to Kristeva's theory of *abjection*. After completing the

installation, I received positive feedback from my cohort and professors. I was delighted that I could transform my

memories into an experience for others to encounter and I felt that it was appropriate to continue expanding my

work within an installation practice.

The Beginnings of Room #237

During the early iterative stages of my thesis work, I reflected upon photographs and videos of my mother's

room in her long-term care facility, in order to create an adaptation of it. To do this, I began collecting materials and

objects that resembled the items from my mother's room. I purchased these objects online, from Value Village, or

they were donated to me [Fig. 4]. I searched online for a medical hospital bed, and managed to find one - which I

painstakingly moved into my small studio space at OCAD University. Once I had collected a sufficient amount of

furniture, I began to alter these objects to reflect my personal experiences.

I began researching artists such as Frida Kahlo, Sofie Calle, and Tierney Gearon, who all use personal

narratives within their work. Intuitively, I started painting each item white and stained them with coffee grounds as a

way to reference the clinical, over-medicalized, appearance of my mother's facility [Fig. 5]. After reading Kate

Mondloch's *Screens: Viewing Media Installation Art*, I became interested in using screens as portals to other worlds.

I felt that this tied in nicely to my interest in *The Gaze*. I used synchronizers to project two videos simultaneously

onto two empty picture frames; one, a close up image of my mother's portrait and the other, a video of us together.

The distinct shape of the projections are reminiscent of a framed picture, an object commonly found in domestic

settings [Fig. 5]. Although I did not end up using these two projections, they sparked an interest in me to continue to

play with projection as a way to engage viewers and provide insight into my experiences with my mother's

dementia.

The Medical Environment

Due to my interest in recreating my mother's room in her long-term care facility, I embarked on an

independent study with Professor Doreen Balabanoff, where I produced a series of twelve photographs entitled

Ghost Stories (2018). I photographed the interior of five long-term care facilities in the summer of 2018 in order to

contemplate the impact that institutional settings may have on the quality of life for residents. During my visits, I

toured the facilities and documented various areas including private resident rooms, salons, dining halls, activity

rooms, and communal rooms. This research contributed to my installation practice by providing me with insight into

a variety of medical environments. The documentary photographs I produced of the various sites functioned as an

"institutional database" that aided me in the process of creating a recreation of my mother's room at her long-term

care facility.

<p align="center">*My Mother's Ghost*</p>

With embodiment in mind, I wanted to provide insight into my mother's experience, from her perspective. I

was inspired by Kara Walker's shadowy projections from her exhibit *Insurrection! (Our Tools Were Rudimentary,*

Yet We Pressed On) from 2002, where the artist used overhead projectors to cast silhouettes of figures and

environments onto the wall. While looking at documentation of Walker's installation, I was struck by how beautiful

the layered compositions were and this fascination was amplified when, looking closer, I realized that the scenes

depicted violent or gruesome scenarios. Perhaps Walker has used violent, projected scenes as a way to evoke abject

responses in viewers, which may unsettle the visual narrative. In an interview with Art21.org, Walker noted that she

purposefully used projection as a means to activate space, where "these overhead projectors serve[ed] as a kind of

stand-in for the viewer, as observers" [58]. Projecting light as a method to reveal narrative stuck with me, and I came

up with the idea of laser-cutting a medical hospital curtain with my mother's handwriting and projecting light

through the fabric to create shadows of the text on the wall of the installation room.

After rereading old emails from my mother, I decided to use messages from her, sent to me, where she

addressed her feelings about her diagnosis with dementia. Once I located a curtain, which was donated to me, I

started tracing my mother's handwriting in Adobe Illustrator. This handwriting was then laser cut onto the medical

---

[58] "Projecting Fictions: *Insurrection! (Our Tools Were Rudimentary, Yet We Pressed On)*" *Art21.org*
https://art21.org/read/kara-walker-projecting-fictions-insurrection-our-tools-were-rudimentary-yet-we-pressed-on/ (Accessed on February 8th, 2019)

curtain. When cutting was complete, I gathered the loose clippings and sewed them back into the laser-cut areas, creating a "stencil" for light to be projected through by the viewer, casting shadows on the adjacent wall. [Fig. 6].

In thinking about light, I returned to exploring projection as a way to incorporate more of my mother's presence. After rummaging through old video content, I came across a video of my mother staggering across a hallway with a walker. Inspired by projection artist Ken Matsubara, I decided that I wanted to create a "ghost" of my mother entering the installation room. I rotoscoped this video, and turned it into a white ghostly shape that enters the room and disappears, only to reappear a few minutes later. I projected this video on the back wall of the installation space and added the sound of a squeaking wheel, which I created by scratching a metal fork across a glass cup.

As I continued to look for opportunities to communicate my mother's story, I searched through old emails and letters. Previous to this, my father had given me a box of my mother's belongings, including journal entries, poems, jewelry and photographs. In this box, I discovered a goodbye note, written from my mother, to me and my sisters. In the note, my mother acknowledges her illness and eventual decline and begs us never to forget that we have each other. It was very painful for me to find this. After digesting this letter, I decided that I wanted to incorporate it within the installation. I bleached it and stained it with coffee grounds and then framed it. For me, this was a cleansing process that allowed me to let go of the emotional turmoil I felt.

My Voice

In an effort to include more of my personal experiences in the work, I decided that I would incorporate more "clues" in the installation, taken from my journal. I started working on a series of drawings that depicted my dreams about my mother. I used watercolour and ink to record images of these dreams in small booklets, accompanied by handwritten descriptions of the dreams [Fig. 8]. The booklets were found during a summer residency at Artscape Gibraltar Point on Toronto Island. They were once used as "Field Guides" for visitors of the Artscape building, as a way to record their experiences; the vintage booklets asked questions inside such as "What is your favourite joke?" to which people scribbled down their answers. Discovering these objects inspired me to think about how I could record my experiences onto the surface of tangible objects. I repurposed them by ripping out the pages, painting them white, and stitching watercolour paper inside. I also decided that I wanted to make my

relationship with my mother more clear for the viewer. I came across an old audio track that I recorded while interviewing my mother about her thoughts and feelings. I linked this audio to the headset of the telephone, allowing the viewer, if they should listen, to discover this intimate conversation between mother and daughter.

In addition to this, I added video footage to the television that correlates to this audio track. In the audio, my mother discusses that she thought she would have been a "happy housewife" at her age. A sense of yearning for home is present in her responses. Knowing this, I decided to shoot footage of the interior of my father's house, where my mother spent most of her time after being diagnosed. I used this footage on the television, along with videos of my mother and myself in her long-term care facility. So as not to overwhelm the viewer with the sight of my ailing mother, I kept the videos of my mother and I brief and intercut them with footage of my father's house. The domestic footage links to the theme of longing for home, enhancing the isolated feeling of the clinical installation room. The video footage of my mother and me correspond to the audio recording on the headset, further inviting the viewer to identify who is involved in the narrative.

Awareness & Impact

It is my hope that my interactive installation, *Louise Snowball, Room #237*, can help to create awareness of issues surrounding dementia, offer a critical perspective on biomedical models of care, and suggest that there are embodied ways of being-in-the-world that are not yet considered by medicine. I would like to state that by sharing my personal experiences, it is not my intention to suggest that biomedical models of care, such as long-term care facilities, are wholly negative institutions. Rather, I am seeking opportunities to share my perspective on some of the issues surrounding these models. It is my opinion that a shift needs to be made from caregiving that focuses solely on medical illness, to caregiving that can include qualitative, person-centred approaches that recognize the importance of embodiment. According to Renée Beard, dementia care is dominated by a biomedical model of medicine that neglects sociocultural and embodied experiences of illness [59]. The "over-medicalization" of the aging

---

[59] Beard, 416.

body, and health care environments, can obscure accurate representations of dementia and encourage unhelpful

dualisms that can engender an elevation of the "mind" over that of the "body" [60].

Biomedical models of medicine that ignore the sociocultural, emotional and embodied components of

illness can run the risk of fostering a separation between the physical, psychological and cultural dimensions of

aging. Many of us live in a "hyper-cognitive" society where our selfhood is considered to be completely dependent

on our "mind". People with dementia, who suffer from severe cognitive impairment are too often conceptualized as

empty shells of existence with little to no control over their minds and bodies and much of the existing literature on

dementia assumes this loss of self to be true [61].

According to Pia Kontos' article *Embodiment and Dementia: Exploring Critical Narratives of Selfhood,*

Surveillance, and Dementia Care, reductions of quality of care in residential and nursing homes has largely been

attributed to negative perceptions of dementia [62]. Kontos challenges these perceptions by examining the lived body

through the theory of *embodied selfhood*, which foregrounds pre-reflective ways of being-in-the-world. The theory

considers that the body has the ability for natural expression through bodily movements, including visual, tactile,

and motor aspects of our bodies [63]. Kontos further contends that there is a relationship between the pre-reflective

body and the social world we live in and that this is demonstrated through the style or content of our bodily

movements [64]. Kontos's theory provides an alternative perspective on dementia that considers a symbiotic

relationship between the body's natural expression and sociocultural environments.

I agree with the concerns expressed by both Beard and Kontos, and it is my belief that some of the issues

surrounding dementia can be challenged by reconsidering the illness as a social, emotional, and embodied

experience that is unique for each individual. Arts-based approaches to care can help to shift the focus toward

creative-expression through emphasizing the body's potential for creative action, innovation, affect, and nonverbal

communication [65]. Artists have the potential to help create a dialogue on issues that surround dementia and suggest

that there are embodied ways of being-in-the-world that are not fully understood or considered by biomedicine. In

---

[60] Kontos, Pia. "Embodiment and Dementia: Exploring Critical Narratives of Selfhood, Surveillance, and Dementia Care" Dementia, 2013: 12 (3) 289..

[61] Kontos, 290.

[62] Kontos, 292.

[63] Kontos, 291.

[64] Kontos, 291.

[65] Kontos, 294.

Louise Snowball, Room #237, I have used a variety of narrative "clues", such as audio, video, and objects with the intention of activating the viewer. I believe that by guiding viewers to participate within a multi-sensory, installation space, it is possible to demonstrate that our bodies shape and enact our experiences, interactions and perceptions in complex, embodied ways. While it has been a difficult journey for me to come to the place where I could share my personal experiences with my mother's dementia, I sincerely hope that my artwork will contribute to knowledge on dementia by providing viewers with a spatialized and affective experience.

Conclusion

On April 11th, 2019, I hosted my thesis exhibition opening along with my sponsors, Scott Russell, CEO of Alzheimer's Society of Toronto and Sue Graham-Nutter, CEO of the Rekai Centres. The event took place at 100 McCaul, in the "Great Hall" space on the 2nd floor, where I had constructed a large installation room [Fig 11 & 12]. During the exhibition, a panel had been arranged to discuss issues surrounding dementia and the state of long-term care. On this panel were Dr. Kathy McGilton, senior scientist at Toronto Rehabilitation Institute, Mary Connell, registered nurse and *The Butterfly Project* manager at Peel's Malton Village, myself, and Sue Graham-Nutter. Collectively, we spoke about our concerns for people with dementia residing within long-term care facilities and addressed the ways in which space, people, and relationships can come together to create compassionate, person-centered care.

Mary Connell discussed her experiences as project manager of *The Butterfly Project* for Malton Village, a person-centred care model developed by Dr. David Sheard in the UK. The model focuses on creating nurturing environments for people with dementia by adjusting the culture of care to emphasize the emotional and social needs of residents. Connell noted that the integration of this model at Malton Village has resulted in a more humanistic approach to caregiving that also considers the wellbeing of staff and families. In addition to this, Dr. Kathy McGilton discussed her research into the quality of relationships between people with dementia and their care providers. She asserted that these relationships have a huge impact on quality of life for people with dementia that reside in long-term care, and that these relationships need to be improved by breaking down stigmas about dementia.

I contributed to this conversation by sharing my personal experiences with my mother's dementia, specifically regarding the environment of my mother's long-term care facility.

I also spoke about a mural that me and two of my colleagues (Dori Vanderhayden and Kristi Poole-Adler) completed at The Rekai Centres in February, 2019. The purpose of this mural was to improve the institutional looking environment at The Rekai Centres by covering the 4th floor interior doors with a painted landscape scene. During the initial planning stage, we compiled five images of landscapes with differing hues (pink, green, blue, yellow, purple) and content (ocean, river, trees, mountain, grass, pond), and approached staff and residents at The Rekai Centres to provide us with their preferences. The image that we used as a reference for the mural was voted highest among staff and residents. In the process of completing this mural, I met and formed friendships with many of the residents. One woman, Lucy, would periodically come up behind me and place her hand on my shoulder. She often appeared distressed and would reach for my hand or gently move the hair away of my eyes. It seemed to me that Lucy needed to connect and communicate on a physical level, and it appeared as if she was comforted by this physical closeness. I shared this impactful experience on the panel to discuss how people with dementia are still able to connect and communicate despite severe cognitive impairment and that it is important for community to engage with residents at long-term care facilities.

Later on in the panel we had time for a Q&A, where audience members could ask questions. I was astounded at how many individuals came forward to share their personal experiences with loved ones and express their fears regarding long-term care. One woman who spoke had recently admitted her mother into long-term care and became emotional while sharing her story. She mentioned that she was fearful that the nurses would not get to know who her mother really is because they would only see another "sick" person in need of care. To address this fear, she wrote a letter to the nurses in her mother's care facility explaining her mother's life journey, including her likes and dislikes. This woman's story touched me deeply, as I experienced similar concerns with my mother. I immediately walked from the panel area toward the audience and asked this woman if I could give her a hug. We shared a long, comforting embrace.

Reflecting upon my thesis exhibition show, it has become important to me that my work facilitate multifaceted dialogues on issues surrounding dementia. I am so pleased that my auto-ethnographic based work could

offer an opportunity to host an informative panel discussion and allow individuals in the room to come forward and share their personal experiences. As the demographic of people who are aging and living longer increases, so too does the risk for dementia. In my case, I experienced the impact of dementia at a young age and because of this I have come to realize that dementia will affect all of us at some point in our lives. Rather than reiterate the frightening statistics on dementia, I think that it is important that opportunities arise where artists like me can share their perspectives and experiences in order to contribute to informed discussions on dementia. Contemporary artists such as Steven Eastwood, Sheena Hoszko, and k.g. Guttman offer critical insight into themes of death and illness, institutional environments and embodiment [66]. Moving forward, I hope to continue my research into dementia and long-term care offering arts-based therapy classes for residents, improving the institutional appearance of facilities, and by contributing my Master's thesis to academic journals and conferences. I wish to expand upon my installation practice through collaborating with artists who have been diagnosed with dementia and continue to work with personal themes of illness, grief and loss in order to raise awareness and challenge outdated institutions.

---

[66] https://www.steveneastwood.co, https://www.sheenahoszko.com, https://kgguttman.com.
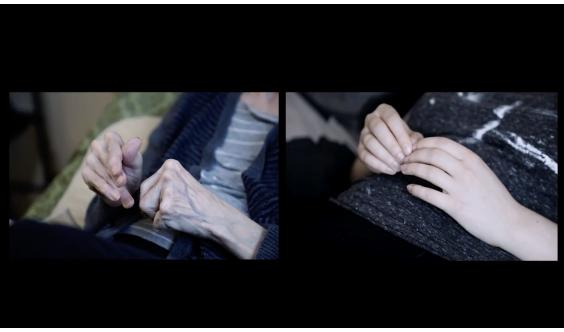
Documentation

Figure 1: Hands of Mother and Daughter (2018)

Figure 2: Don't Cry, It's Not That Bad (2016)

Figure 3: First Installation (2017)

Figure 4: Collection of Objects (2018)

Figure 5: White, Stained Objects & Projections (2018)
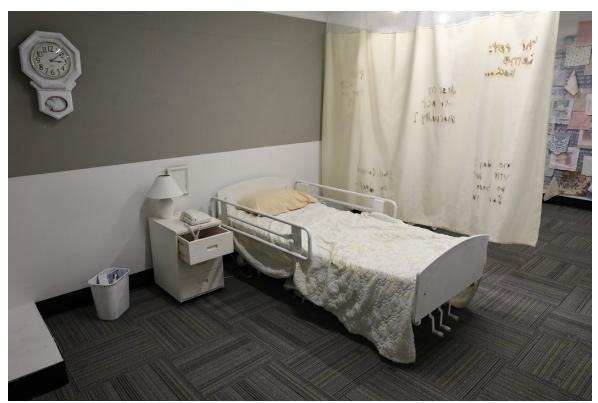

Figure 6: Laser Cut Curtain (2018)

Figure 7: Full Installation View (2019)

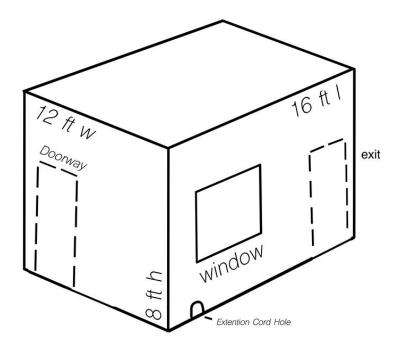*Figure 8: Telephone & Booklet (2019)*

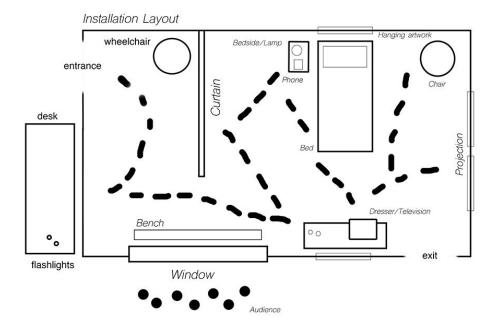*Figure 9: Design of Physical Room (2018)*

Figure 10: Design of Physical Room (2018)

Figure 11: Exterior Installation View (2019)

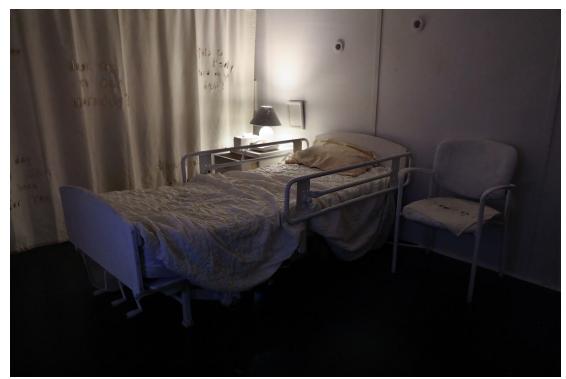*Figure 12: Exterior Installation View of Peepholes (2019)*

Figure 13: Interior Installation View (2019)

Figure 14: Interior Installation View of Projection (2019)

Bibliography

"A Look Inside the Louise Bourgeois House, Just How She Left it" nytimes.com
https://www.nytimes.com/2016/01/24/arts/design/a-look-inside-louise-bourgeoiss-home-just-how-she-left-it.html
(Accessed February 8th, 2019)

Ahmed, Sara. "Queer Phenomenology: Orientations, Objects, Others." Durham: Duke University Press, 2006. 1 - 2.

Beard, Renée. "In Their Voices: Identity Preservation and Experiences of Alzheimer's Disease" Journal of Aging Studies 18, no. 4 (2004): 415-428.

Brathwaite, Brenda. Schreiber, Ian. "Challenges for Game Designers" Boston: Course Technology (2009), 1 - 28.

Clement, Ryan. "Playing the Story: The Emergence of Narrative through the Interaction between Players, Game Mechanics, and Participatory Fan Communities." www.uwpsace.uwaterloo.ca
https://uwspace.uwaterloo.ca/bitstream/handle/10012/12681/Clement_Ryan.pdf (Accessed February 8th, 2019), 19.

Davis, Daniel. "Dementia: Sociological and Philosophical Constructions" Edinburgh: *Social Science and Medicine, Vol 58*, (2004): 369-378.

"Declarative (Explicit) Memory & Procedural (Implicit) Memory" human-memory.net
http://www.human-memory.net/types_declarative.html (Accessed March 15th, 2019)

Doyle, Judith "Warmware: Mnemonic Art and Design Research", Mobile Nation, Riverside Press, M. Ladly and P. Beesley, eds. 2008, p. 199

Engles, George L. "The Need for a New Medical Model: A Challenge for Biomedicine" New York: *Science*, New Series, Vol. 196, No. 4286, (1977): 129-136.

Findlay, Deborah. "The Medical Gaze: Medical Models, Power, and Women's Health" Atlantis, Vol. 18, Nos. 1 & 2, 1992 - 1993. 105 - 121.

Foucault, Michel. "The Birth of the Clinic: An Archaeology of Medical Perspective" New York: Vintage Book Publishing, (1973): 3 - 20.

Kristeva, Julia. "Approaching Abjection" *Powers of Horror: An Essay on Abjection*, New York: Columbia University Press, (1982): 1 - 31; 211.

Kontos, Pia. "Embodiment and Dementia: Exploring Critical Narratives of Selfhood, Surveillance, and Dementia Care" Dementia, 2013: 12 (3) 289 - 310.

"Louise Bourgeois's Powerful, Confessional Poems Will Now Be Published for the First Time- and You Can Read One Here" news.artnet.com https://news.artnet.com/art-world/louise-bourgeois-writing-glenstone-1268621
(Accessed February 8th, 2019)

McAfee, Noëlle. "Abjection" *Julia Kristeva*. New York & London: Routledge Publications, 2004: 44 - 51

McCabe, Janet, Holmes, Dave, Lauzon, Sylvie, and Gagnon, Marilou. "Subjectivity and Embodiment: Acknowledging Abjection in Nursing" and "Encountering the Other: Nursing, Dementia Care, and the Self" *Abjectly Boundless*: *Boundaries, Bodies and Health Work.* (2016): 251 - 283.

Merleau-Ponty, M. "Phenomenology of Perception" London: Routledge, (2002): 235 - 403.

Mondloch, Kate. "Screens: Viewing Media Installation Art". University of Minnesota Press, (2010): 63.

Millet, Stephan, "Self and Embodiment: A Bio-Phenomenological Approach to Dementia" Sage Publications, 2011, http://dem.sagepub.com/content/early/2011/06/14/1471301211409374 (Accessed Jan 20th, 2019)

"Projecting Fictions: *Insurrection! (Our Tools Were Rudimentary, Yet We Pressed On)" Art21.org* *https://art21.org/read/kara-walker-projecting-fictions-insurrection-our-tools-were-rudimentary-yet-we-pressed-on/* *(Accessed on February 8th, 2019)*

Rokeby, David. "*Transforming Mirrors: Control and Subjectivity in Interactive Media" DavidRokeby.com,* *http://www.davidrokeby.com/mirrorsnavig.html (Accessed Jan 2nd, 2019).*

Romdenh-Romluc, Komarine. Routledge Philosophy Guidebook to Merleau-Ponty and Phenomenology of Perception. London, Routledge (2010): 62 -102.

Rudge, Trudy, and Dave, Holmes. "Subjectivity and Embodiment: Acknowledging Abjection in Nursing" and "Encountering the Other: Nursing, Dementia Care, and the Self" *Abjectly Boundless*: *Boundaries, Bodies and Health Work.* 2016: 273

Wilson, Yolonda, et al. "Intersectionality in Clinical Medicine: The Need for a Conceptual Framework" *The American Journal of Bioethics*, 19(2), (2019), 9 - 20

Whitney, Shiloh, "Affect and Difference in the Philosophy of Merleau-Ponty" McGill University, 2013:http://digitool.library.mcgill.ca/webclient/StreamGate?folder_id=0&dvs=1548021436204~204 (Accessed Jan 20th., 2019)