Tic: exploring Tourette syndrome with analog photography

by

Katelyn Lux Brewer

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Director of Thesis: Angela Franks Wells
Major Department: School of Art and Design

Tourette Syndrome is a neurological disorder characterized by involuntary movements and vocalizations known as tics, which can significantly affect the daily lives of those diagnosed. This work explores the historical and contemporary perceptions of Tourette Syndrome, highlighting the misconceptions within the medical community and culture broadly. Beginning with an examination of the first documented descriptions of the syndrome, the research delves into the stigmatization of individuals with Tourette's, linking past misunderstandings to modern portrayals in media. I employ a Diana F+ camera to express the emotional and physical complexities of living with Tourette Syndrome. Through analog photography, I embrace the imperfections of both the medium and the condition itself. This artistic endeavor seeks to promote dialogue and understanding of Tourette Syndrome, advocating for greater awareness and support for individuals affected by it.

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Katelyn Lux Brewer

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Director of Thesis: Angela Franks Wells, MFA

Thesis Committee Members:

Daniel Kariko, MFA

Matt Egan, MFA

DEDICATION

For Parker

My light, my heart, my soul

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INTRODUCTION

Tourette syndrome is a neurological disorder characterized by repetitive, involuntary movements and vocalizations called tics. These tics can range from mild to severe and can include blinking, throat clearing, grunting, sniffling, and other involuntary movements. The tics may worsen during periods of stress, anxiety, or excitement, and may improve or disappear during periods of relaxation or focus. The exact cause of Tourette syndrome is unknown, but it is thought to involve a combination of genetic and environmental factors. The area most affected by the syndrome is the basal ganglia, located at the base of the forebrain. This area regulates motor control, eye movement, and executive functions. There is no cure for Tourette syndrome, but various treatments such as medications, behavioral therapies, and support groups, can help manage symptoms and improve quality of life ("About Tourette Syndrome.").

It was discovered by Gilles de la Tourette in 1885 when he described nine patients who suffered from involuntary movements: echolalia, echopraxia, and coprolalia. When most people think of Tourette syndrome, they often think of what is called Coprolalia. Coprolalia is the excessive and uncontrollable use of inappropriate language. This affects 1 in 10 people with Tourette's and is the least common form of the syndrome. Echolalia is the repeating and mirroring of other's words or actions. Echopraxia is the repetition of actions such as physical movements which is the form of tics I experience the most. Tics vary in complexity and include blinking, grimacing, shrugging, and sniffing while others involve touching objects, repeating the same words, or making obscene gestures. The CDC reported in the United States that 1 in 360 children, 6 to 17 years of age receive a Tourette syndrome diagnosis, but it often goes undiagnosed ("Data and Statistics").

Discussion of Tourette syndrome is important because it is a neurological disorder that affects many individuals around the world and can significantly impact their daily lives. People diagnosed with Tourette syndrome are often perceived as faking, lying, or unintelligent. They are seen as willingly disruptive and thus unable to have successful, fulfilling lives. We live in a time of increasing social awareness and empathy for neurodivergence. People with Tourette syndrome deserve to be a part of that conversation. This paper will give an overview of the history of Tourette syndrome, explore the contemporary practice of art as it relates to mental and physical disorders, provide an analysis of depictions of Tourette syndrome in popular media, and present my photographic series, “tic,” which explores my personal experience with Tourette’s, and lastly will unpack the artistic methods and practice by which the series was produced.

CHAPTER 1: HISTORY OF TOURETTE SYNDROME

The first description of Tourette syndrome was written in *Malleus Maleficarum* (1487) by catholic clergyman, Heinrich Kramer, in which a priest is described as having uncontrollable movements and sounds. These symptoms are thought to be signs of demon possession and it is no surprise this book became widely used in witch-hunting and was known as the witch-hunters bible. *Malleus Maleficarum* describes individuals who are possessed by demons and exhibit involuntary movements and vocalizations, which could be interpreted as a manifestation of Tourette Syndrome (Goetz et al. 346).

The diagnosis of Tourette Syndrome did not exist during the period in which the *Malleus Maleficarum* was written, and it was not until the late 19th century that a formal diagnosis of Tourette Syndrome was established. According to the text, a possessed clergyman may exhibit various signs of possession, including speaking in tongues, convulsions, and other abnormal movements or behaviors. The *Malleus Maleficarum* also describes a process for identifying and exorcising demons from possessed individuals, including priests. The text suggests that exorcism should be performed by a trained and authorized exorcist, and it provides detailed instructions for conducting an exorcism. During the witch hunts of the 15th to 17th centuries, people were often accused of being witches or possessed by demons if they exhibited unusual or aberrant behavior. This behavior could include involuntary movements or vocalizations, which might resemble some of the symptoms of Tourette Syndrome. Many of the behaviors that were attributed to witchcraft or possession were likely the result of a wide range of medical and psychological conditions that were poorly understood at the time. The accusations made during the witch hunts were based on superstition, prejudice, and misinformation, and not on any actual

evidence of wrongdoing or possession. The persecution of individuals who were accused of witchcraft often had devastating consequences, including imprisonment, torture, and execution (Germiniani et al. 547).

This belief in witches manifested itself into hysteria which was a term used for women up until the 1980s. Hysteria was used to describe a wide range of psychological and emotional symptoms in women, including anxiety, depression, and somatic symptoms such as pain or paralysis. The term is no longer used as a diagnostic category in modern medicine, as it is outdated and based on sexist and patriarchal attitudes towards women's mental health (Tasca et al. 110). Throughout the historical record of mental disorders, and since the invention of photographic processes in the early 19th century, there have been many approaches to photographing individuals who live with both physical and mental disorders. Some of these approaches were highly exploitive and others sought to capture their humanity.

CHAPTER 2: PHOTOGRAPHIC HISTORY OF DISABILITIES

The photographic history of individuals with disabilities is rich and complex, evolving alongside broader societal attitudes toward disability. *Picturing Disability* by Robert Bogdan explores the representation of people with disabilities in visual culture, particularly through photography. The book examines how images have historically shaped societal perceptions of disability, often perpetuating stereotypes and stigmas. Bogdan critiques both the artistic and documentary practices that depict disabled individuals, highlighting the importance of context and intent behind these images. By analyzing various photographic works and their impact, Bogdan encourages critical engagement with images of disability, urging viewers to recognize the humanity of disabled lives (3).

The photographic history of disabilities begins with beggar cards. The history of beggar cards, often referred to as "penny cards" or "beggar's tickets," offers insight into societal views on poverty, charity, and marginalized individuals. Beggar cards are printed cards that featured a short description of the person's circumstances, sometimes including their name, age, and specific needs. Some cards even included a moral or religious message, appealing to the compassion of passersby. The goal was to give a card to a passerby in hopes the beggar would receive money as an exchange. Disabled beggars were often allowed to maintain a presence in urban areas, where they could easily interact with a larger number of people. The cards helped establish a form of identity for those experiencing poverty (22).

Most of the asylums were in poor condition and experienced overcrowding. Photographers were hired to make the asylum appear appealing to families with disabled loved ones. The patients were often dressed in nice clothes for the occasion to create an illusion of

cleanliness and perfection. The conditions of most asylums were so bad, that photographers no longer photographed the inside. The photographs of the buildings became popular and were picture-perfect illusions of a seemingly nice place. These photographs became postcards that were sold and bought (57).

In the 1850s and 1860s, photography emerged as a tool for documenting patients in asylums. Physicians used photographs for clinical purposes, aiming to record symptoms and behaviors associated with mental illness. Patients' photographs were often labeled with harmful phrases such as "cretin" or "mongoloid". Patients who did not have an apparent physical disability were labeled with their conditions. For example, a full-frontal portrait of a man with no apparent disability was labeled with the word "echolalia".

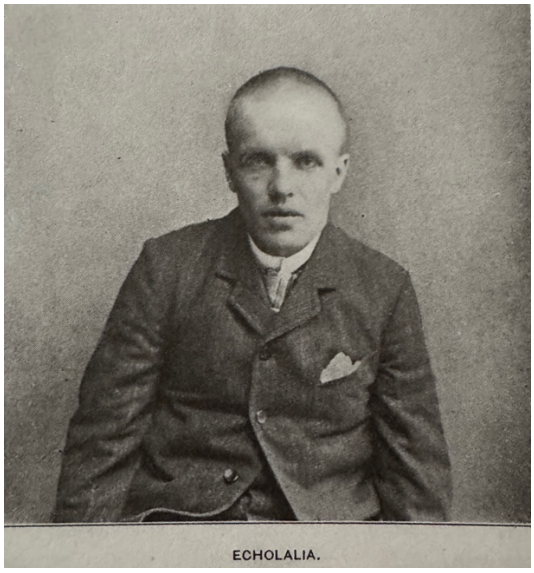

Figure 1: "Echolalia." From Barr, 1904

While this can be associated with other conditions, it is mostly associated with Tourette's. Without this label, the viewer would never know what his condition is. While labels may be helpful in the medical community, they are damaging to the individual often reducing complex identities to simplistic categories (93). In my photographs, I choose how I am depicted by setting up my composition and choosing my own poses. No outside labels are placed upon me as I

individually name each photo in my series. The distinction between exaggerated portrayals and nuanced representations emphasizes the ongoing challenge of achieving accurate depictions of Tourette Syndrome in the media, revealing how cultural narratives can influence both public perception and individual experiences. These dynamics have continued to be born out in contemporary depictions of Tourette's.

CHAPTER 3: CONTEMPORARY MEDIA DEPICTIONS

There are instances where Tourette Syndrome is portrayed in a sensationalized or insensitive manner in the media and popular culture. The misrepresentation continues today in films such as characters blurting out obscenities and being portrayed as stupid and ditsy. Films that portray the syndrome are often classified as comedies. Specific examples of insensitive portrayals of Tourette syndrome are in films such as *Deuce Bigalow: Male Gigolo* (1999), *Harvie Krumpet* (2003), and an episode of South Park, "*Le Petit Tourette*" (2007). Tourette syndrome is primarily portrayed in a lighthearted or funny way so as not to create a feeling of uncomfortableness within the viewer (Calder-Sprackman 228). As a child, I was often asked to "tic" in front of family and strangers. My tics were used as entertainment which films and tv shows falsely representing Tourette syndrome perpetuate.

A more serious depiction of Tourette Syndrome appears in the 2019 film noir, *Motherless Brooklyn* written and starred by Edward Norton. The film portrays Lionel Essrog, a lonely private detective with Tourette Syndrome although this is never mentioned. Lionel describes Tourette's as "threads in my head" and throughout the film, we see how it affects him. He also describes his tics getting worse when he is stressed, upset, angry or excited. He has no control over certain sounds and movements, and this is seen as he twists his neck and blurts out random phrases. The repeated bodily movements, face-shrugging, face-making, blinking, and arm jerking Lionel does is an accurate characteristic of someone with Tourette Syndrome. Lionel also repeatedly shouts words, sounds, and phrases which is an accurate depiction of vocal tics. Lionel tells people that he never got a name for his condition and was beaten as a child for having it in the orphanage he grew up in. Lionel also has OCD which is often a co-occurring condition in

those with Tourette's (Norton, *Motherless Brooklyn*). The examination of artists who express their personal experiences through their work reveals an absence in the representation of Tourette Syndrome, underlining the importance of more creators sharing their stories to enhance awareness and understanding of this condition through art. Though there is a lack of representation within the art world of Tourette's, it is instructive to review how artists who live with other disorders represent themselves within their work.

CHAPTER 4: DISORDERS IN ART

Many artists have used their personal experiences with mental or physical conditions as a basis for their work. Utilizing the formal qualities of photography to communicate their intimate, personal experiences with their conditions. When researching Tourette syndrome representation in art, I have found little to no artists who have made work about the syndrome. I found many photographers who use their physical conditions as themes in their work such as Mari Katayama and Ariana Page Russell. Katayama suffers from congenital tibial hemimelia, where the lower bones in her legs did not form, causing her to be a double amputee as age nine. She has created self-portraits with embroidered objects and prostheses made from leather to use her body as a living sculpture. Katayama's images are about the performance of identity and the things that shape it. She believes that tracing herself connects with other people and her everyday life can connect with society and the world ("Mari Katayama").

Figure 2: "Bystander #016" by Maria Katayama

Russell has a condition called dermatographia where her skin becomes easily red and welted when scratched. Russell explores her condition by creating fleeting adornments on her skin and then photographing herself. The reaction of her skin is involuntary, and she externalizes internal functions by scratching designs into her skin. She represents an uncontrollable response that reveals internal sentiment. Russell utilizes her work to share her condition which about five percent of the general population experiences (“Ariana Page Russell”).

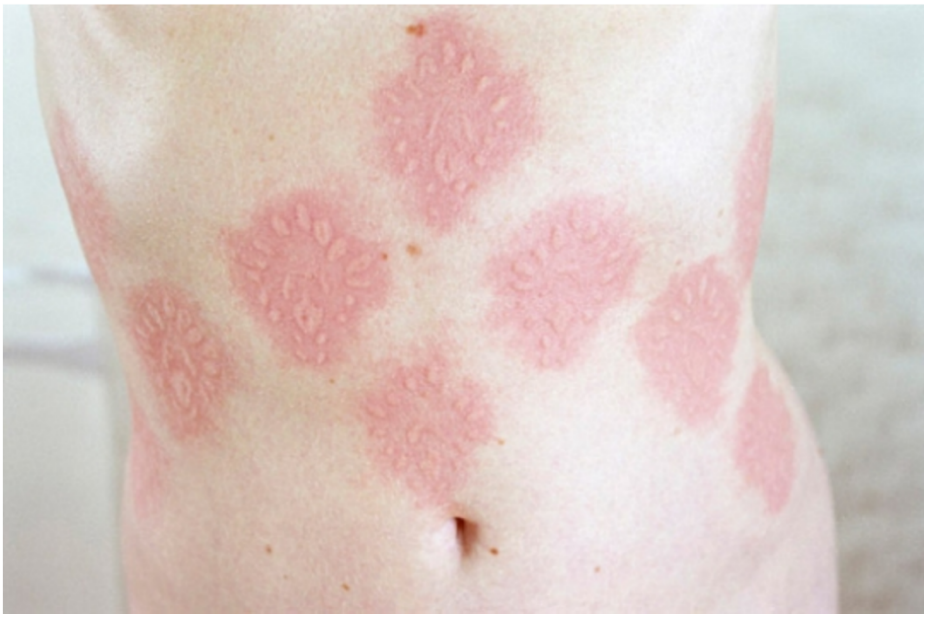

Figure 3: "Flora" by Ariana Page Russell

My journey with tics began in childhood, with a concerning head movement that led to a diagnosis of Tourette Syndrome, a realization that intertwined my experiences with those of my father, who struggled with obsessive-compulsive disorder; this connection emphasizes the complexity of genetics and mental health within families.

CHAPTER 5: GROWING UP WITH TOURETTE SYNDROME

My experience with tics started as a young child as I would repeatedly throw my head backwards hard and fast. My parents became worried about this as I had an invasive and quite scary head surgery at the age of four years old and they feared this might be a result of that. I was taken to a doctor and diagnosed with Tourette's.

Plate 1: it began with a lurch

I wondered why I was the only one in my family to have tics, making me feel like an outcast. Growing up, I knew my father had obsessive-compulsive disorder as he was diagnosed with it, and I have memories of watching him act out his obsessions. I never realized that my father's

diagnosis with OCD is the cause of my Tourette's. I learned that if you have a parent with OCD, you have a high chance of having Tourette syndrome and/or OCD.

Plate 2: inherited worry

In *Passing for Normal: A Memoir of Compulsion*, Amy Wilensky has both Tourette's and OCD and was finally diagnosed in her early twenties. Amy's situation is like mine as her tics started with a head tilt as a child. Her father always had compulsions and obsessions such as driving back to his office to make sure the fax machine was turned off (Wilensky 202). My father did similar acts as he would repeatedly jiggle the doorknob to make sure it was locked or stand in front of the refrigerator for as long as he could with a tight grip on its handles to assure himself it was shut.

Plate 3: over closed door

Like Amy, I remember watching my father perform these rituals as a child and I also developed obsessions and compulsions of my own. I was constantly worried about dying or the absurd idea that the veins on my inner wrists would puncture through my skin. One day, worried that my family would die, I took a green crayon–it had to be green–and wrote my family's initials on the wall above my parents' bed. After doing so, I felt relief that I had saved my parents and sister from dying. The writing in the center above the bed where we all slept would protect us. The repetitive thought ended, and I felt like I could function again. My mother was upset I had written on the wall and asked why I did it. I lied to her and said I did not know why because I was too embarrassed to tell the truth. I was petrified they would die if I did not write on the wall and part of me to this day still believes I saved my family from dying. Tourette Syndrome has become a compelling focus for my work, not only because it is a part of my own experience, but

also due to the lack of artistic representations that address it; this absence raises the question of how to convey a condition that many people around me struggle to understand.

CHAPTER 6: MY ARTISTIC PROCESS

Tourette syndrome became an interesting topic for my work as not only do I have the syndrome, but I have found no artists have created work about it. The question is: how can I represent a syndrome which many people around me do not understand? I never talked about my experience with having Tourette's nor did I ever tell anyone I had it. Growing up, I was too embarrassed and scared of what people would think of me. The fact of the matter is, living with Tourette syndrome has made me feel isolated, mistreated, ridiculed, and ignored. These feelings are universal within the human experience and these themes are what viewers can connect with in my work.

I am using analog photography, and my camera is a Diana F+ which is a plastic-bodied toy camera with limited controls. The Diana camera was created in the 1960s in Kowloon Bay, Hong Kong. The camera appealed to users because it had a simple construction. The meniscus lens (convex-concave lens that is thicker at the center than the edges) created low-fidelity images reminiscent of impressionist paintings. The focus was gentle, giving the photos a moody, dreamlike quality (Cheeo). This camera can sometimes be difficult to use due to its limited functions and this is a lot like Tourette's for me. My tics make it hard to complete tasks at times and I feel limited because my body is consumed by tics.

Plate 4: splinter

With my camera, I am not completely dependent on its features. I welcome the imperfections of this camera such as light leaks, blurriness and wonky compositions. These imperfections are in my favor much like the imperfectness of Tourette's. For my process, I can be in the moment and spend more time focusing on what I am feeling both emotionally and physically. Tourette syndrome is both physically and mentally exhausting for me. I have several tics that sometimes make activities difficult for me. For example, one tic I have, and it is my worst tic, is the erratic blinking and squinting of my eyes. When it is at its worst, I have trouble focusing, reading books, watching TV and even driving. I feel as if I spend most of my life with my eyes closed. This is extremely difficult for me and using analog represents the inability of not being able to see. I use mirrors because I constantly imagine what others see of me when I tic. I

do not like to see myself when I tic and I wish I could conceal myself from others including myself. Sometimes the inside of a mirror is the nastiest place to be.

Plate 5: the inside of a mirror is the nastiest place to be

Another tic I have is clenching my throat which is considered an "invisible tic" because it cannot be seen by other people. Sometimes I have difficulty swallowing my food due to this tic and even feel as if I am choking. This of course, always creates panic for me, and I want this feeling of panic to be represented in my work. While I shoot, I fling, jump, and spin my body in front of the camera to create a feeling of anxiety. In this work, I represent the feeling my tics create for me. The movement in my photographs are a manifestation of how my body reacts when ticking which is always full of frustration.

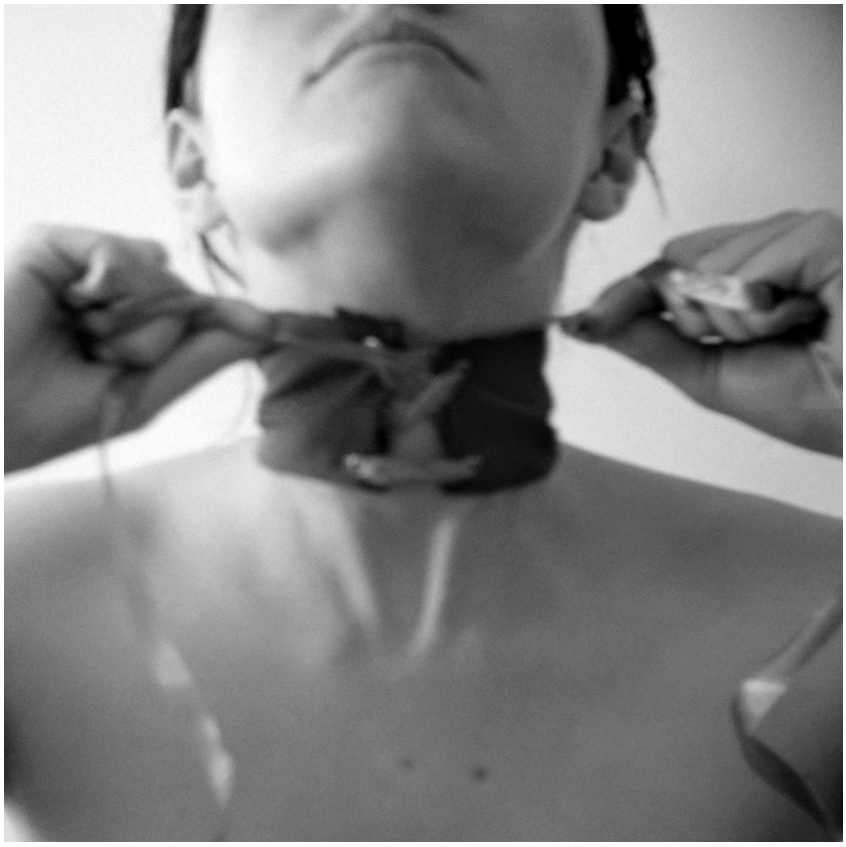

Plate 6: some tics don't yell

In my work, I am exploring how I interact and assert myself within these places just as I do day to day in my own life. When I take these photographs, the questions I ask myself are: am I being concealed within this location, or do I stand out? “How do the mirrors and objects I bring interact with the space? Does it add to my sense of self, or does it erase my sense of self? Can my reflection be seen? Do the abandoned locations contribute to what I am trying to say? If I flail myself about, will I be a ghostly shadow or a distorted figure? All these questions help me think about why and how I am taking these photographs. My work aims to challenge the misconceptions about Tourette Syndrome, especially those perpetuated by the medical community, emphasizing the critical need for more accurate information and a deeper understanding of how this condition impacts individuals.

Plate 7: erratica

CONCLUSION

In conclusion, my work addresses the pervasive misconceptions surrounding Tourette syndrome within the medical community. Many doctors incorrectly reassure parents that children will outgrow their tics by adulthood, which is not the case for many individuals who continue to tic throughout their lives. This misunderstanding can leave families unprepared for the ongoing challenges of living with Tourette syndrome. There is no magic age as to when tics will end. There are periods where they may slow down or stop but tics often come back, especially in times of stress. In an *Ask Dr. K* form, a mother informs Dr. Anthony Komaroff, the physician and professor at Harvard University, about her young daughter's tics. Dr. K replies "It is rare for kids with tics to develop Tourette syndrome. I'll bet your daughter's tics will go away." This is a harmful response because once a child myself with tics, they did not go away and I continue to have tics ("Insights, TMI Tourette Mama"). Doctors should tell parents that it is a possibility their children's tics may never go away so families can prepare themselves as well as their children on how to cope. This harmful response leads people to believe that adults cannot have Tourette syndrome. Based on the 2020 US Census, it is estimated that 350,000 to 450,000 children and adults have Tourette syndrome (Tinker, Sarah C et al.).

My work shows that adults with Tourette syndrome exist and that it is a syndrome that is sometimes difficult to deal with. This syndrome is something I live with every day, and it is a part of me. Through my work, I aim to shed light on the reality of adult experiences with Tourette syndrome, illustrating the complexities and emotions tied to it. Talking openly about Tourette Syndrome can significantly shift society's perception by raising awareness, reducing stigma, and fostering empathy. It helps debunk myths, emphasizing that tics are involuntary

rather than intentional and highlights the complexity of the condition. Sharing personal stories and showcasing successful individuals with Tourette's humanizes the disorder, promoting acceptance and challenging negative stereotypes. This conversation can also create a more inclusive environment, encouraging reasonable accommodations and policy changes, while advocating for greater understanding and research.

Ultimately, discussing Tourette syndrome encourages a culture of neurodiversity, empowers individuals with the condition, and cultivates a society that values patience, compassion, and acceptance for all. This work is deeply personal, reflecting my own journey and the daily realities I face. Ultimately, I hope to foster understanding and awareness around a topic that remains largely unspoken, encouraging open dialogue and support for those affected.

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APPENDIX 1: ADDITIONAL PHOTOGRAPHS IN THESIS EXHIBITON

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