Hope in the Shadows

Nasim Salehi

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Abstract

The realm of pain and suffering interwoven in the intricacy of human existence often remains concealed, hidden beneath everyday life. *Hope in the Shadows* attempts to shine a light on hidden pain to reveal a fraction of the sufferings that lie beneath our skin and the pains that we learn to live through. Spanning an eighteen-year journey through the convoluted maze of the healthcare system, the narratives combine personal struggles with a critical examination of patient care, particularly through the eyes of those suffering from Multiple Sclerosis. Venturing on a journey through the corridors of healthcare, this narration juxtaposes personal trauma and systemic critique to weave the threads of personal experience with a critique of the healthcare system. At its core, the stories serve as testimony to the numerous tribulations every individual has to confront in the healthcare system. From the fears of being in the small, enclosed space of an MRI machine to the endless wait times for these critical but often late tests, the narrative reflects the silent anguish encapsulating the lives of individuals. Through an art exhibition, this work endeavors to alter the intangible agony of medical imaging into a tangible and clear form, emphasizing the necessity of a more efficient and caring healthcare system. This work is an artistic journey that mixes personal struggle with a wider critique, pushing for a new way of looking at patient care.

Hope in the Shadows delves into the paradoxical juxtaposition between the importance of technological innovation in diagnosis and treatment and the blunt realities of lived experience for those dealing with the pain of chronic illness. Within this intricate web of personal, social, and political dynamics lies a call to action—an impassioned petition for acknowledgment and addressing of systemic inequities. By interweaving personal narratives with keen critiques of the current healthcare system, this project endeavors to engender a heightened awareness of the complex challenges confronting patients.

Central to the thematic underpinnings of this endeavor is the metaphorical motif of ‘cages’—both literal and figurative—that serve as allegorical representations of the existential boundaries imposed upon individuals navigating the labyrinth of the healthcare system.

By combining my personal story with the broader analysis, I aim to highlight the human element that often missed in statistical and clinical discussions. This blend of academic review, data analysis, and personal narrative aims to offer a holistic understanding of the current state of MRI scans and the critical issues faced by patients, setting the stage for discussions on potential improvements in the field.

Through this evocative imagery, viewers are invited to contemplate the profound solitude and circumscription experienced by patients, fostering a deeper understanding of the imperative for empathy, solidarity, and systemic change.

Acknowledgements

This thesis is a mosaic of countless moments, challenges, and lessons, each painted with the unique hues of the individuals who have journeyed alongside me. At its core, it is a testament not just to academic endeavor, but to the profound human connections that have guided, shaped, and illuminated this path.

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[1] https://en.wikipedia.org/wiki/Ukraine_International_Airlines_Flight_752

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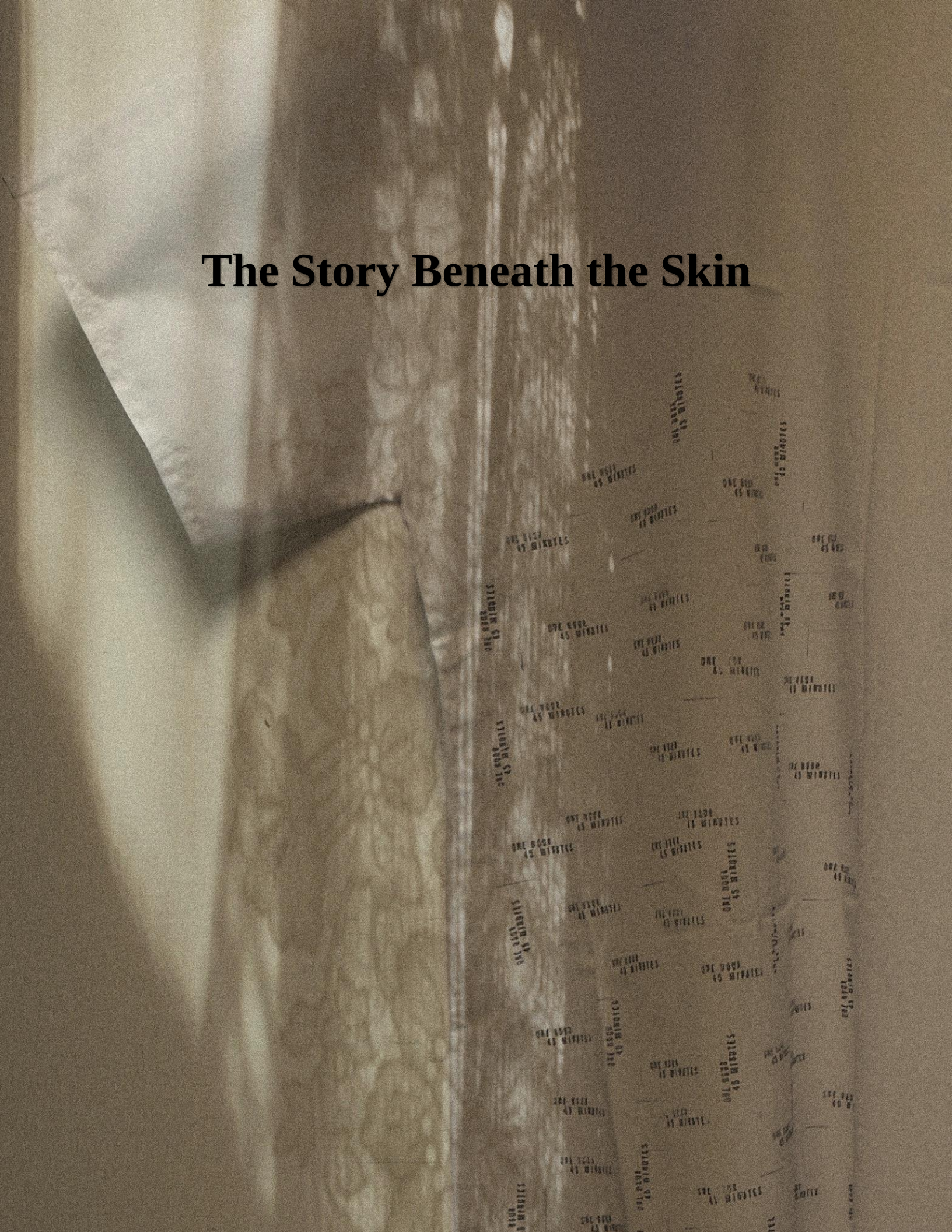
The Story Beneath the Skin



A New Reality

> "Any coward can fight a battle when he's sure of winning; but give me the man who has pluck to fight when he's sure of losing. That's my way, sir; and there are many victories worse than a defeat."
> George Elliot

I will sit on the chair. A hat will be placed on my head, capturing an image of my brain. A circle of color, a circle of black and white. I feel a strange excitement. I'm engulfed in anticipation, wondering how my brain will look at the age of twenty-three.

Will it showcase the colorful and grayscale moments of my life? This thought fills me with a sense of excitement.

As the wind brushes against my face through the car window, I reflect on the fact that only two months remain until my birthday. Seeking a checkup for the numbness in my finger as advised by my family doctor now seems like the right decision. Amidst this, I feel a deep tiredness from the stressful days that have passed, especially the exhausting efforts of organizing a wedding. These memories now seem distant and obscure.

I can't think of any of those dark days that have passed. I leave my car in a parking lot which feels like it is suspended between the earth and the sky. It's getting late. Inside the hospital, a nurse instructs me to change my clothes and wait. "Someone will come and call you," leaving me puzzled about the connection between my outfit and a brain scan.

Why should I change my clothes? What does my brain image have to do with my pants?

Hearing my name, I follow the sound and enter a bright, white, and cold room dominated by a tunnel-like machine. Another nurse guides me to lie down and stretch out. She hands me a black ball and puts a cap on my head, securing it to the bed. The ticking sound twists in my brain. She informs me that I'll need to wait for about forty minutes inside the machine, after which I'll be brought out for an injection for the color scan. The possibility of a burning sensation is mentioned, but she reassures me it's normal.

Many questions fill my eyes, implying there is something to guess afterward! As a blanket is placed on my feet, the nurse mentions that the entire process will take approximately an hour and forty-five minutes. My body begins to heat up at the thought. An hour and forty-five minutes? Did I hear that right? Do I have to lie down straight in this tunnel for that long?

The ironing bed moves into the tunnel. My eyes follow the path. This is the worst place in the world, undoubtedly. I can't help but feel like I'm entering the most daunting place in the world, a life experience akin to a grave.

My breath doesn't rise. I experience dizziness and nausea simultaneously. A wave of dizziness and nausea hits me, yet my breath remains steady. I clutch the black ball in my hand.

A voice says, "Dear, we haven't started yet."

I say, " I don't want this to start". Despite my protest, the scan begins, accompanied by a series of strange and loud noises.

Trapped for 105 Minutes

> "Your mind will never stop telling you unpleasant stories. That is what minds so. So, let's be realistic. The fact is, you will get hooked up and reeled in by these stories again and again. That's bad news. The good news is you can make dramatic improvements. You can learn to get hooked much less often. You can learn to recognize much faster when you have been hooked and you can learn to get much better at unhooking yourself! All these abilities will help to keep you out of the happiness trap." (Harris and Hayes 69)

I close my eyes tightly, overwhelmed by fear. The ceiling of the MRI seems to constrict my breathing space. The sounds grow louder and more terrifying.

"Why am I here? Why did no one tell me an MRI isn't just a simple X-ray test?" My heart rate skyrockets. A voice whispers in my ear, "take a deep breath," but it only sends an error message through my mind.

I want to scream out loud, "Enough, damn it all." This cursed blanket draped over my legs feels like a journey through hell. I never even cover my legs in my regular dreams.

In my head, I repeat to myself, "Be patient. Endure. It will be over soon." Tears flow, obstructing my breathing path, streaming towards my ears.

"Why must I be here?" I squeeze the panic button. "Please, get me out. Please..."

Sobbing ensues as the bed begins to move outwards. A blinding white light from the ceiling strikes my eyes. "Please, take this helmet off my face."

If she had come to my rescue just a few seconds later, I would have suffocated.

The weary nurse says, “Dear, you need to stay like this for two more hours.”

I protest, “I’m sure I’m fine. The doctor just wanted me to have a simple check-up, not to experience death.”

A middle-aged doctor opens the door, approaches me, and gently says, “Please let it finish, for your own sake. Stay calm and give yourself some peace. I will make it quick.”

The nurse leaves a tissue in my hand and with a smirk says, “You’re not a child, my girl. Don’t do this and let’s get it over with.”

I lie back down. Harder. Close my eyes. The helmet is placed over my head. The blanket is removed, and the bed slowly enters the tunnel again. I can feel the distance between my eyes and the MRI ceiling. My hands touch the side walls. The annoying noises continue. A voice from the microphone announces, “You’ll be out in a few minutes for the injection. Please, don’t move and maintain your position”. A sharp needle pierces my arm, and a burning sensation begins. Now it feels like all the cells in my body are on fire.

I press the panic button again. The doctor says, “It’s almost over, you are doing great.” I realize there’s no escape. I’m certain I won’t come out alive from this cursed tunnel. The burning sensation intensifies. I wiggle my fingers to assure myself I’m still alive. My legs turn over and over, maybe a thousand times.

Someone whispers in my ear, “It’s done.”

The nurse unlocks the helmet from the bed. She supports my head to help me sit at the edge of the bed. My body trembles. I can’t even sit up. I stare into the MRI tunnel.

“I was here for one hour and forty-five minutes?”

It feels like a massive weight is suspended over my head. The nurse helps me to the chairs in the hallway. The doctor meets me halfway and says, “Your MRI results will be ready soon.” My lifeless body is left on the hallway chairs. Who would believe I’ve returned from the grave!

The Unseen Storm

> "It begins with numbness on her left leg. Then it spreads…it takes two more years for Meredith O'Brien to learn what is causing that numbness. She has to adjust to the restrictions MS imposes on her. It is a life, altered." (O'Brien 1)

The MRI must be repeated, this time at the hospital. My doctor, skeptical, finds it hard to believe that my symptoms —a numb left finger and days of relentless headaches—could indicate MS. He offers me a faint glimmer of hope. "No, my dear, it's a mistake, unclear, not evident. For your own reassurance, let's do another MRI."

Leaving the doctor's office, I'm overwhelmed with thoughts as I head home. I quickly search for information about MS (Multiple Sclerosis)— its causes and treatments. What I find is disheartening: the cause is unknown, and there is no cure yet. MS can drastically alter one's life, making walking or talking difficult, and even causing double vision. The possibility of needing a wheelchair or losing the ability to move or speak terrifies me. I'm deeply concerned about what the future holds.

Darkness clouds my vision as I wonder, 'What does double vision really mean?'

But death isn't an immediate concern. How old am I again? When does everything get worse? Is it really incurable? A wave of despair washes over me as I think about all the things I might never do again. The silence in the taxi feels like a heavy blanket, smothering my hopes and dreams. As I stare blankly out of the window tears begin to blur my vision, the reality of my situation sinking in like a stone in a deep, dark lake.

The taxi stops at my doorstep. I want to exit but my legs won't move. Could the symptoms manifest this quickly?

I retreat to my room, searching every website I can find. There's no sign of hope. I stay in my darkened room until dinner, paralyzed by the fear of standing and possibly collapsing. My computer screen doubles, confirming my worst fears. A profound, unsettling terror grips me.

At dinner, my father breaks the silence, "What did the doctor say?" My mother, concerned, adds, "You've been secluded in your room since you returned. Tell us, what did the doctor say?"

With my head bowed over my soup bowl, my voice barely audible, I confess, "I have MS."

Dad's confusion is evident. "What's MS?" None of us at the dinner table knew of the disease until that moment.

I try to sound optimistic. "I need to be careful, but I'll recover soon."

Dad reassures me, his voice both firm and gentle, "You're just tired, nothing more. Rest, and you'll be back on your feet. I promise you that." As we continue eating, Younes's eyes reveal his own internet research. He understands the daunting future that lies ahead, not just for me but potentially for him too, having just entered my life. In my heart, I'm screaming for help, but the words don't come out. It's like drowning in an ocean of my own fears, with no lifeline in sight.

We eat, chat, and force laughter, but inside me, a volcano simmers, ready to erupt.

The Quiet Struggle

> "You have set yourselves a difficult task, but you will succeed if you persevere, and you will find a joy in overcoming obstacles." (Keller 172)

In the emotionally charged atmosphere of a hospital waiting room I find myself seated next to a young girl, about sixteen or seventeen, dressed in a similar white hospital gown. Tears stream down her face quietly, echoed by her mother's soft sobs. She desperately pleads with her mother to find a way to avoid the MRI, her fear tangible in the tense air.

My mom sits beside me, praying and gently wiping her own tears. She doesn't really understand what an MRI involves, but she knows I'm the one who's ill.

The nurse calls the young girl's name, and the room's atmosphere becomes heavier with her escalating cries and pleas. Her mother, in a voice filled with desperation, begs the nurse to be gentle, fearing the pain her daughter might face. The nurse assures her, "It's painless". Among those of us waiting our turn, a sense of resigned maturity sharply contrasts with the girl's youthful fear.

The nurse now says more sternly, "Do you want to skip the test? You're delaying everyone else."

With great reluctance, the girl is led inside, the door closing behind her. Faintly, we hear her pleas for a shorter procedure, echoing her profound fear.

My mother, her eyes wide with concern, turns to me and asks, "Does it hurt?" I try to comfort her with a simple "no". She asks to see the MRI images on my phone. I show her. Her

eyes widen in shock, “You have to go into that tunnel?” I nod, unwilling to explain further and worsen her mood. I don’t want her to know anything more.

Soon, the door opens again, revealing the girl supported by two nurses. Her mother, filled with concern, rushes to her side. The girl, looking exhausted and defeated, leans heavily on her mother. The nurse informs them that the MRI couldn't be completed and advises speaking to the doctor. The mother, her face marked with worry, helps her daughter back to their seats, their movements reflecting their physical and emotional exhaustion.

They call my name. My mother’s voice breaks as she calls out to me. I turn to reassure her with a smile, “Don’t worry, I’m okay”. But inside, I’m far from okay.

I lie down on the metallic bed, my arms at my sides, ready to enter what feels like a tunnel of doom. This time, I’m certain that the ordeal of this hour and forty-five minutes is likely nothing compared to what awaits me for the rest of my life. As the bed moves into the tunnel, it feels like curses from heaven and earth descend upon me.

Flickers in the Dark

> “No matter how bad the situation you're in, no matter how much pain you may be suffering, start by taking a few deep breaths. If you’re breathing, you know you're alive. And as long as you’re alive, there’s hope.” (Harris and Hayes 144)

It is almost unbelievable how quickly I found myself falling into this deep, lonely hole. Time has flown by; an entire year has passed. Throughout this whole year, not a single night went by without my sleep being disturbed by nightmares. These weren’t just any nightmares but clear, worrying dreams about a future where I'm stuck in a wheelchair, a future that seems too close for comfort. This year has been a strange kind of life, one where my constant companions have been nothing more than bandages, clean gauze, and the chilly touch of needles.

Here I am, sitting with my legs crossed in a small, poorly lit basement room. My eyes are glued to the TV screen but I’m not really watching it. My thoughts are elsewhere, overwhelmed by a fear so strong that it made me come here an hour early, afraid of feeling regret later. Across from me there is a middle-aged man. He seems unaware of my struggle, casually flipping through a magazine as if he doesn’t have a single worry.

This setting in this moment in time feels surreal. I’m caught in a space between a past I wish I could go back to and a future I'm scared of with all my heart. The room, with its dimming light and the unchanging sound of the TV, feels like a separate bubble from the rest of the world—a world that seems to be moving on without me. Here, in this small, tight space, time stands still, but at the same time it also speeds by, leaving me to deal with my fears and the unknowns of what’s coming next.

“The magazine seems like a good idea,” I think. But when I try to grab it, I shake so much that it falls from my hand. I lean over to pick it up and as I see the headline, I freeze. I press my head against the wall behind the chair, thinking, “This is going to be my reality for the rest of my life. My whole life!” Can life really force me to spend all my time dealing with this tough disease and endless MRI scans? I tell myself change can happen. The world is getting better; things will improve. Desperately, I calculate my age and wonder how many years I might have left.

The elderly man doesn’t look away from me. I look away. He asks which part of my body we’re scanning today. “My brain and spine,” I respond. He notes my anxiety, asking if it's my first time. “No, it’s my third,” I say, knowing deep down it won’t be the last.

He seems to sense my fear, hesitating between speaking and staying silent. “Can I tell you something?” he finally asks. I smile broadly, welcoming his words. He shares a story of his first MRI, how his overwhelming fear led to a heart attack, his hospitalizations, and the numerous appointments he canceled until today, when he almost didn't show up yet again. Curiosity overtakes me and I ask about his condition. “I have MS,” he says, suspecting I might not have heard of it. “It doesn’t get better, but I should be thankful it's been manageable so far.”

When the nurse calls him, he stands, dragging his left leg. I can’t take my eyes off his struggle. The nurse offers help, but he insists, “I'm in the best shape I've been in recently.

Curious, I ask how long he's been living with MS.

Twenty years,” he says, his voice trailing off as he walks away.

Twenty years? I look down at my own legs, wiggling my toes inside my shoes, grateful they still move. A wave of unexplained joy washes over me, marking a significant yet silent victory in my mind.

Frozen in Time

> “The reality is life involves pain. There is no getting away from it. As human beings, we are all faced with the fact that sooner or later we will grow infirm, get sick, and die. Sooner or later we all will lose valued relationships through rejection, separation, or death. Sooner or later we all will come face to face with crises, disappointment, and failure. The good news is that, although we cannot avoid such pain, we can learn to handle it much better and create a life worth living despite it.” (Harris and Hayes 14)

Moving ahead of me, she sings in a melancholic rhythm. The snow falls gently to the ground; it is deeply satisfying. We reach the subway doors together, and I hold them open for her. With a charming tone she thanks me. I'm searching for my metro pass, my bag so full it might burst at any moment.

My hand was grated, not cut, last night. The attempt to find the card is futile, adding to the pain in my hand. I search for my headphones in my pocket and finally find my metro pass. I must be on time for my MRI today, finish work, and then head to an exam. With seconds to spare before the metro doors close, the best move is to dive in. The music from my headphones is loud and I sense that others can hear it. A bump on my shoulder; it is the lady who was singing this morning. She gestures to pick up my headset, which I do.

“Good morning,” she says, infusing kindness into the greeting. I respond eagerly, “Oh, good morning. It must be a good day with this gentle snow”. She nods emphatically, wishing she could talk more but couldn't. At the next station two seats free up. I suggest she sit, but she insists it doesn't matter. We both end up standing near the empty seats. She excitedly talks about her work, life, her garden, the cottage she recently bought, and starts to talk about her child.

As she gets off at her stop, apologizing, I see her off with a simple smile, wishing she had shared her child's story. In the MRI waiting room which lacks windows a painting of an autumn landscape tries to break the underground claustrophobia. Staring at the painting, I wonder about her child's fate. A greeting breaks my solitude and I look up to see her, causing me to rise in surprise and happiness. “You? Here? Incredible, glad to see you, although this isn't the best place”. She laughs, sits beside me, and talks about everything but her child. I awkwardly ask if her child goes to school and after receiving no response curse myself for asking.

The silence between us grows heavy. I take out my e-reader. She says I'm too young to hear her son’s story. Surprised, I mention my own son, but she dismisses it, suggesting my still youthful optimism means that I'm not ready. The room fills with the scent of her egg sandwich and coffee. She leans in, asking if my condition was diagnosed. I confirm, “MS”. She admits ignorance about it.

As I move closer to the door in anticipation of my call she asks about my son’s age. I tell her he's battling his body and just turned eleven last week. Urged by a choking silence, I ask about her child. Tears fill her eyes as she reveals they’ll disconnect his oxygen on Friday, forever thirty-five, diagnosed too late with cancer that ravaged his body. This dreaded MRI! Eight months of fighting just for this appointment.

The MRI door opens; I introduce myself to the nurse who jokes about my eagerness. Asked if I knew the woman, I affirm, “Yes, very well”. The nurse advises against eating eggs in crowded waiting areas. As I enter the MRI tunnel, the nurse’s voice and that of the others blend, but hers remains distinct.

“Friday, if they cut off the oxygen, forever thirty-five!” Lying in the MRI, I hope never to face such trials with my child.

Celebrating Life in the Clasp of MRI

> “At the end of the body -at the far extreme of schematization, at the pitch of dryness and intellection-are representations that are no longer about the body, where the artists are really thinking about other matters.” (Elkins 283)

The initial intense pain and heat spreading through me, alongside the heavy breath sinking into my chest, serve as the first signs of death. Here I am, undergoing an MRI for the tenth time. How many more sessions lie ahead? This place is the only one where I can distinctly hear the constant pounding of my misfortune. It is one of the many times I’ve chosen to be alone. It feels like wanting to die just to start over again. It is as if you've planned to visit yearly, to view the frayed edges of your existence with clearer vision. I lay my hands beside me and, with insistence, agree to try the headphones for once. I close my eyes, nearly touching the depths of darkness. I feel the bed moving. Three, two, one—welcome to an hour and forty-five-minute reception in a cramped, iron cage.

It is impossible. I can’t endure this for even a second. What a painfully absurd idea—trapped, with your head immobilized and headphones clamped over your ears. The rotten smell of nostalgia rises. I remember the last clothes of my childhood, a red chair, a simple blue shirt, two chocolate cakes that mom and dad bought separately for the birthday of a child who was supposed to be aborted. Dad's loud voice, “What happened to the Moein’s song?” My tiny fears slowly paint themselves on the walls of the MRI tunnel.

In the second scene, we are on our way to Anzali, Dad blasting Moein in the car, urging us to sing along, and we join in, though hesitantly. Upon arrival, I'm practically invisible. Being so small and frail, they overlook me at lunch. Guests keep arriving at the cottage and I struggle to find anywhere to sleep until it's nighttime.

I squeeze the black ball in my hand. Nothing happens. Again, twice, thrice. Why doesn't this damn thing work? I shake my legs, hoping someone would notice. The music stops, a voice asks, "Is there any problem?" I say, stop this stupid DJ setup you've got going. If it goes on for another second, my corpse will be coming out of here. The sound stops, but the headphones remain beside my ear. Just having the headphones near my ears feels uncomfortable. I want to scream, but my voice finds no audience here.

I press the ball again. A voice whispers, "Is something wrong?" I say, get these headphones away from me. The voice says to just endure a few more minutes until this phase is over. The MRI sound fades, but I'd rather have a sledgehammer hit my head than have these damn headphones covering my ears in this situation. Either time has stopped for me, or they've forgotten someone is seriously getting suffocated under her unlucky memories here, now with headphones too.

I don't know how many minutes have passed. They've engaged me in an unfairly matched battle. The bed moves slowly. Through all that pressure, I see light. The nurse lifts the headphones, adjusting my head. I hold her hand; it is devoid of warmth. The nurse says, "These headphones usually help ease the MRI experience for many, what made it difficult for you?" I say, "I prefer the resonance of life's fluctuations, ma'am, the very sound of life that has led me here".

The rails move smoothly over each other. I enter the tunnel. The MRI technician's voice amplifies my chill. "Don't be afraid. Take a deep breath. Don't be afraid. Breathe deeply". Fear

not, you have forty-five minutes to resurrect your life. Forty-five minutes. I no longer think; my thoughts converge into darkness.

Who would believe, when I get out of here, that I wore my white clothes, lay on the white bed, listened to Moein to not hear the hammers falling on my head? Who would have believed that one day that innocent six-year-old face would celebrate her thirties with her aches in an MRI!

Magnetic Fields of Sorrow

> “There it sat
> in the projecting angle of the bridge flange,
> as I stood aghast and looked at it –
> in the half-light: shapeless or rather returned
> to its original shape, armless, legless,
> headless, packed like the pit of fruit into
> that obscure corner – or a fish to swim against
> the stream – or a child in the womb prepared
> to imitate life, warding its life against
> a birth of awful promise. The music guards it,
> a mucus, a film that surrounds it,
> a benumbing ink that stains the sea of our
> minds – to hold us off-shed of a shape close
> as it can get to no shape” (William Carlos Williams, Elkins 34)

Since morning, I haven’t had anything but water. I need to be ready for an MRI at midnight. My stomach aches terribly, but it is better than feeling nauseous inside the MRI machine. I’m lying listlessly on the couch, while my mom knits a scarf for me. She has been saying since morning that she will come with me to the MRI, but I’ve been refusing. I scroll through my phone, seeing pictures of friends who have gone to Iran for the January holidays. I stare at their photos, cursing myself for the thousandth time for having to be away from our beloved homeland enduring this biting cold in a foreign land, far from my loved ones. No answer comes to mind, only the certainty that nothing is worth enduring a lifetime away from my loved ones.

I start getting dressed more quickly. A firm set of footsteps approaches me. My mom holds her phone screen in front of my eyes. “What does this say, Nasim?” I’m speechless, my vision

blurs. A Ukrainian plane crashed in Iran’s sky? Mom can't hold back her tears. I say, “Let me sit down and see where we can find reliable news and the names of the passengers”. Her cries echo in my ears as she says, “Does it even matter who the passengers were?”

I feel suffocated. I’m definitely going to be late. It is an hour drive to the hospital. Why do I have to drive this route for an hour at this time of night, in this condition, and then drive back home for another hour in even worse conditions? Mom forgets to say she will come with me. The swift movements of her fingers across her phone screen frustrate me more. I say goodbye to her quietly. She says, “Pray nobody’s dead. Take care of yourself. When are you coming back? Actually, I wanted to come with you so you wouldn't be alone”. I convince her that her coming wouldn’t change anything. An unusual chill seizes my body. Behind the wheel, I check the news coverage on Iran.

The car’s speed is beyond my control. Sometimes, I feel like I’m soaring; other times, I’m a turtle stuck in mud. I call all my friends who had gone to Iran for the Christmas holidays. Five don't answer. Two do, saying they are flying back on Turkish Airlines, confidently stating that the crash was due to a technical fault. I can’t find the hospital’s main entrance; every door I find is closed at this late hour. “Where is this cursed door?” I have no idea how to get inside. I make my way to the emergency room and ask for directions to the MRI. I am ten minutes late. I check the latest news on the plane crash. All the passengers were burned. 176 people. In about eighteen seconds. Twenty seconds. Does it even matter? They’re all gone.

As I change my clothes, it feels like the fire from the crashed plane envelops me. The nurse calls my name. I hesitate for a few seconds before entering. Now, I must enter this metal cage which is like an additional inferno. Outwardly, everything proceeds as usual, except the nurse says the MRI will take about an hour. She doesn't know how much those extra forty-five minutes could

help me in this state. I hear strange noises. My mind is filled with the screams of helpless passengers who, in a cylinder not on the ground, not in an MRI, but in the sky, turned to ash in the blink of an eye, and what dreams were shattered in the darkness of the night.

My entire body feels hot; I feel as if the MRI is plummeting at high speed. Where to? I don't know. I don't know why my mind imagines a tragedy. I don't know why it doesn't believe in a technical fault. But what other rational explanation could there be!

It is as if the plane is crashing in the MRI. I'm holding Ryan's hand; we're holding on to the seats. I clutch at my heart. My mouth is sealed in horror. My eyes record the fears of the children. Can those twenty seconds even be described! The thought of my child burning throws me against the MRI walls. I scream for help. No one hears me. Again, I scream for help. Nothing. A third time. No response. Like the passengers whose cries even God didn't hear.

A hand shakes me. "Are you okay? Were you sleeping?"

I feel like my ashes are scattered on the bed.

The nurse calmly says, "It's good that you rested". I tell her, "A plane crashed tonight, and 172 people burned in less than twenty seconds. In your metal cage, I dreamt of collecting the ashes of my loved ones". Her eyes widen in shock. She says, "Are you joking?" Tears won't stop. I leave.

I leave for the cold air and freezing rain to slap me in the face at 1:50 AM on January 8th.

I start the car. Pictures of the passengers and their smiles fill the social media pages. Mom calls, "Where are you? It's 3AM." I am frozen in the twenty seconds it took for 176 innocent passengers to burn, deliberately killed.

The Art of Loss

> "If you love somebody deeply and you lose that relationship, whether through death, rejection, or separation, you will feel pain. That pain is called grief. Grief is a normal emotional reaction to any significant loss, whether a loved one, a job or a limb. And, once the pain is accepted, it will pass in its own good time." (Harris and Hayes 27)

I visualize the deepest images in my brain to escape the torment of passing time through an MRI scan. Trapped in the most remote place on this colorful planet in an MRI, my breaths can't even reach its short ceiling, hindered by the mask on my face.

Hadi Bahmani has been killed[2]. He was eighteen, perhaps protesting water scarcity or something else. He was a protester, seeking nothing beyond basic welfare. His mother has invited guests to accompany her son's blood-stained body to its final resting place. The guests have come to mourn over his body, applying henna to their hands and feet, so she can bury her dreams with her young son.

Thousands of perspectives flash before my eyes, thousands of dark angles in sheer white light. Hands encircle the waist of a grieving woman as other women connect in shared suffering, their clothes black, the green of despair.

Young men are torn between clapping, chest-thumping, and tearing their clothes. The weight of sorrow bows the guests' heads over their bodies as mourning women in black attire wail.

[2] https://www.en-hrana.org/tag/hadi-bahmani/

A woman alone in the middle of the field surrenders herself to a dance of pain. A basket passed from hand to hand carries henna, flowers, and colorful handkerchiefs. No one sees the ground, but I do, imprisoned in the MRI. I see the earth trembling under their feet, the black handkerchiefs twirling above their heads. The sky is colorless; mountains sway behind the crowd; everything moves.

I must believe all images are directed, all events pre-written on paper. Everything in its right place, movements, sound, music, all orchestrated to perfectly display pain. I wish MRI technology could record the images passing through my mind. The images lighting up in my brain under pressure and pain never appear as vivid outside the MRI.

I see every detail in this cold rebellion.

Where can I unravel this magnificent pain bit by bit?

I see my homeland, a land that nurtures artists. In every form, these people are magnificent. I wish they would abandon their routines and witness the grandest performance of pain in the world from my brain's perspective.

The bed slowly exits the tunnel, and I return from the farewell ceremony of the lifeless body of an eighteen-year-old boy, whose mother mourns his thousand buried dreams. I find my way to the restroom. Sometimes, crying is the cure for humanity, long, silent cries within the MRI, at the metro station, in class, unconscious sobs during meetings with a thousand strangers. Sometimes, crying is the only refuge.

A girl in the bathroom mirror fixes her lipstick. Beside her, I splash my face with water for the thousandth time to collect my tears.

She says it's no use. I look at her; she says it's no use, your face will get injured.

I say it helps.

She says your eyes have learned to cry involuntarily.

She leaves a pack of soft tissues beside me.

I say thank you, I don't need them.

She insists, "You need them, a packet of soft tissues and a long hug".

She packs up her makeup and leaves, saying, "Sorry, hugs don't work for my own pains either".

I look at my hands, wrap them around myself, and tell the mirror, "This is the longest hug in the world!"

I carry my loneliness, along with the unshed tears of Pejman's mother, a packet of soft tissues, and the longing for a long hug, out of the bathroom.

I have forty-five minutes to cry on my way to Ryan, then to put on the robe of motherhood. Ryan smiles, saying my face has turned pink from the cold. I laugh and tell him, "It's better than your red, frostbitten lips, kiddo," and try to forget the dark day that has passed over me.

My hands grow stronger, ready to embrace all pains at once.

An Anchor in the Icy Depths

> "So that story was ended; somebody began another, about that satyr whom Latona's son surpassed at playing the flute, and punished, sorely, flaying him, so the skin all left his body, so he was one great wound, with the blood flowing, the nerves exposed, veins with no cover of skin over their beating surface, lungs and entrails visible as they functioned." (Ovid, Elkins 108)

On the morning before my MRI, the mere thought of swallowing a drop of water seemed enough to make me sick. A strange stomachache filled my chest, making even the simple act of brushing my teeth difficult. While preparing Ryan's school snacks, I pondered whether any task could be more challenging than standing at the counter, making a chicken sandwich at this moment.

On the way to school he asked, "Should I eat an egg, bacon, and cheese sandwich?" "Definitely," I said. "You have to eat too," he insisted. "Not happening," I replied. "I won't eat it alone. If you don't eat, I won't either." I wanted to tell Ryan that just one bite could potentially end me.

I stopped at Tim Hortons. "Grab two sandwiches, whatever you like, and don't forget the hot chocolate," I instructed.

No matter how far you drift away, how much you've forgotten, or how much exhaustion, darkness, and pain have piled upon you, light always finds a way through.

The technician's face, tasked with guiding me into the MRI's daunting realm, bore signs of fatigue. She gestured towards the bed, instructing me to lie down. From this angle, her exhaustion

seemed even more pronounced. She lifted my legs, asking if I wanted my eyes covered. “I’ll close them as much as I can; I don’t need it,” I assured her. “Are you comfortable?” she inquired. “Could you place a pillow under my legs? I know it will help with the back pain,” I requested. The MRI bed then slid forward, entering the tunnel like a ship into the night.

I needed to find a memory or a conversation—anything to immerse myself in for at least an hour to endure the upcoming forty-five minutes as the machine started its barrage of noises. I attempted to let images overpower the annoying sounds.

It was those Thursday evenings, waiting impatiently behind the door for my dad so we could go for a walk. He’d call minutes before arriving, signaling me to be ready at the door. I’d been ready for hours, waiting eagerly by the intercom to dash out as soon as he rang.

He held my hand tightly, irrespective of my age. Whether I was four, seven, or ten, he’d ask, “What’s for dinner?” If it was something I disliked, he’d lay out all the culinary options of our long street before me. “You’re eating it,” he’d say. “No,” I’d counter, “If you’re not eating, neither am I.” He’d pretend he was already full. “Then, I’ll just have whatever’s for dinner at home,” I’d relent. He’d loudly claim, “I’ll eat it, I’ll eat it, damn it,” and we’d laugh, setting off to find the least appealing meal we could, ensuring mom wouldn’t find out we’d never “learn better.”

Dad had it all—high blood pressure, diabetes, uric acid, cholesterol, fatty liver, and the heart of a ten-year-old boy. We’d have dinner, enjoy ice cream, savor hot broad beans, and cap it off with hot chocolate as if breaking from routine.

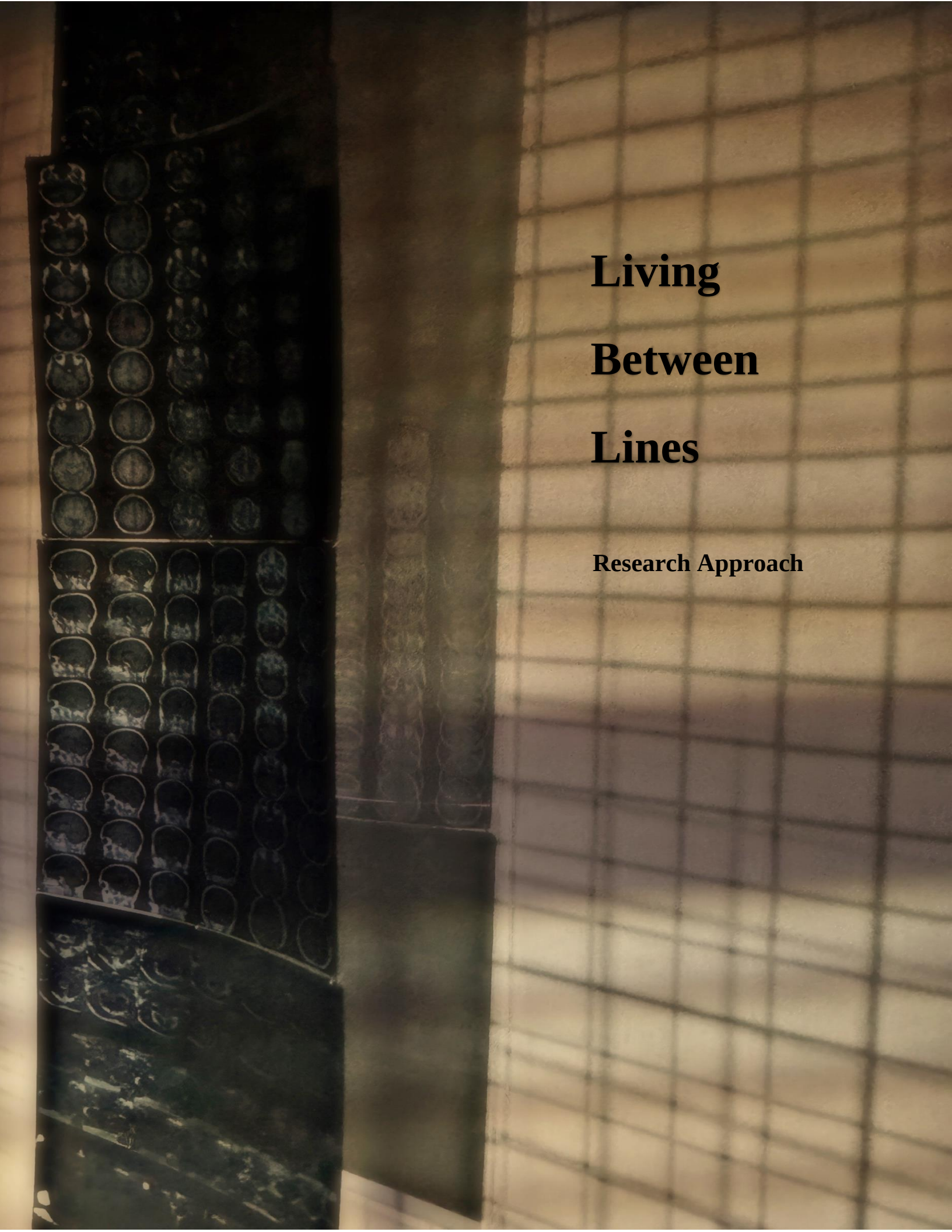
I could hear my laughter echoing in the cold, breathless tunnel of the MRI.

Dad would eat just so I would eat, occasionally giving into my whims with love, even when he decided to be careful.

Dad had held my hand firmly as we walked, ate, laughed, and refused to succumb to the end. Since the morning, when I had impulsively stopped and told Ryan to pick whatever he wanted, promising we'd share it together, Dad had been there. He had taken Ryan to school and brought me to the MRI. Dad still remained by my side on the cold iron bed of the MRI, under a snow-filled sky, squeezing my hand even tighter.

As the bed slowly moved out of the tunnel and the injection began, a burning sensation spread through my body. Dad's voice was lost among the loud MRI sounds, but his grip on my hands never wavered. How far could he see me? How far into my fears would he come? The noises began to overshadow all images, casting shadows.

Dad stood at a distance, watching, as I faced my fears head-on and bit into life once more, even though it felt like his hands could no longer reach mine.



Living Between Lines

Research Approach

Research Approach

In this section, first a brief discussion on the importance of Magnetic Resonance Imaging (MRI) scans in modern medical diagnostics is provided. MRI provides detailed images of soft tissues, organs, and other internal structures of the body, which include essential diagnostic information that might not be visible through other imaging modalities like X-rays or CT scans. This advanced imaging technique is pivotal for diagnosing a wide range of conditions, including but not limited to, tumors, brain disorders, and spinal injuries, making it an essential tool in the modern medicine.

Following the discussion on the importance of MRI in healthcare, we shift our focus to the list of challenges that patients face before and during an MRI procedure. These challenges not only include logistical issues such as long waiting times for appointments and the scheduling of procedures at late hours, which can disrupt patients' personal schedules and increase their stress levels but also extend to the psychological distress faced by individuals undergoing the scan. Specifically, patients who experience claustrophobia or have an aversion to confined spaces find MRI procedures particularly scary due to the enclosed nature of the scanning equipment. This anxiety can be so severe that may negatively impact the quality recorded images or even lead some patients to refuse the scan altogether, potentially delaying crucial diagnoses. Moreover, the noise produced by the MRI machine, which can be surprisingly loud, adds another layer of discomfort for patients. Children, as well as adults with heightened anxiety or sensory processing disorders, may find this aspect of the procedure especially challenging.

In each case, I will present a detailed review of research papers that explore each problem's adverse effects on patients' wellbeing. By reviewing various studies and research papers, I aim to shed light on the adverse effects these issues can have on the patient experience, encompassing not only the physical discomfort and inconvenience caused but also the psychological impact taken

on individuals undergoing MRI scans. Through this detailed review, I aspire to highlight areas where improvements can be made in the patient care process, from scheduling and facility design to the provision of supportive measures for those with anxiety, thereby enhancing the overall MRI experience for patients.

In addition to the literature review, this section also includes a quantitative analysis of MRI wait times across Canada. This is achieved by utilizing raw data sourced from the Canadian Institute for Health Information. The objective of this analysis is to offer a statistical viewpoint on the accessibility and operational efficiency of MRI services across the country. By examining and interpreting this data, I will examine the current state of MRI wait times, identifying regions that face significant delays and pinpointing potential bottlenecks in the system. This analytical approach enables us to understand the broader implications of wait times on patient care and the overall effectiveness of healthcare delivery related to MRI diagnostics. It is my hope that this analysis will pave the way for discussions on potential strategies and interventions that could be implemented to improve service delivery, reduce wait times, and enhance the patient experience in accessing MRI services in Canada.

Finally, this section will be enriched with insights from my personal journey, employing an autoethnographic research approach. As someone who has lived with Multiple Sclerosis (MS) for 18 years and undergone annual MRI scans, my experiences offer a unique, lived perspective on the subject. This personal narrative will delve into the emotional and physical aspects of undergoing repeated MRI scans, the impact of wait times on disease management, and the psychological effects of living with a chronic condition that necessitates such frequent interactions with the healthcare system. By combining my personal story with the broader analysis, I aim to highlight the human element that often missed in statistical and clinical discussions. This blend of

academic review, data analysis, and personal narrative aims to offer a holistic understanding of the current state of MRI scans and the critical issues faced by patients, setting the stage for discussions on potential improvements in the field.

Magnetic Resonance Imaging

This subsection provides a review of research around MRI wait-time and its negative impacts on patients with Multiple Sclerosis (MS). In addition to reviewing research papers, I perform quantitative analyses on MRI wait times in Canada using raw data sourced from the Canadian Institute for Health Information (CIHI) website[3].

MRI is an important medical diagnostic imaging technique to create detailed images of organs, tissues, and other structures inside the body. It utilizes non-unionized electromagnetic radiation to capture detailed anatomical images, offering a method that appears to be without any exposure related hazards (Katti et al. 1). Figure 1 shows a series of brain MRIs, which can used to detect brain tumors, traumatic brain injury, developmental anomalies, multiple sclerosis, stroke, dementia, infection, and the causes of headache.

MRI is often preferred over other imaging techniques such as X-rays and CT scans because it does not involve ionizing radiation, which can be harmful to the body in large doses[4]. One study conducted in the United States in 2007 suggested that approximately 29,000 future cancers could be related to the radiation from the annual CT scans (Berrington de Gonzales et al. 1). Furthermore, in a comprehensive literature review published in 2021, it has been concluded that there is an increasing evidence from epidemiological data that CT scans can lead to cancer (Hemaya et al. 2). Unlike CT scans, which use ionizing radiation, MRI uses magnetic fields and radio waves, making

[3] https://www.cihi.ca/en

[4] Ionizing radiation can affect the atoms in living things, so it poses a health risk by damaging tissue and DNA in genes. https://www.epa.gov/radiation/radiation-basics

it a safer option, especially for patients requiring multiple scans or those who are sensitive to radiation, such as pregnant women and children.

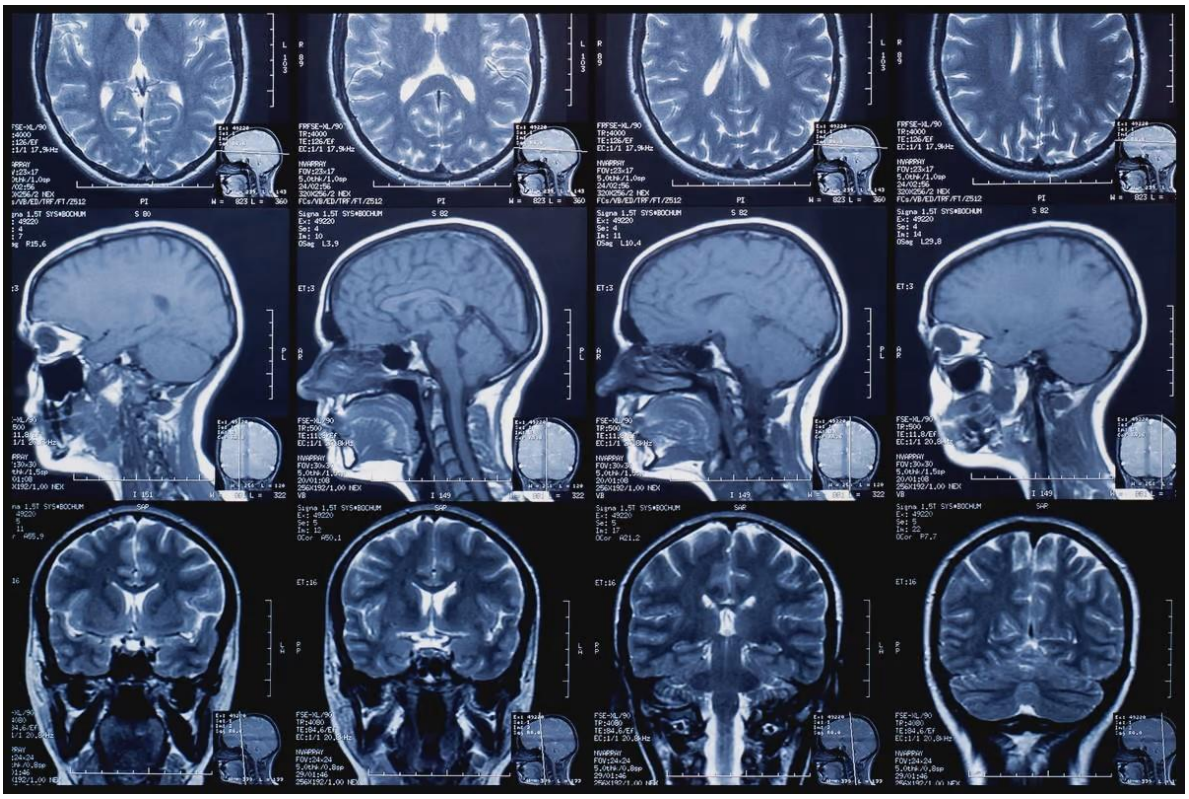


Figure 1: MRI of the Brain[5]

Additionally, MRI can produce high quality images in multiple planes, offering a more comprehensive view of the body's internal structures, which can be crucial for accurate diagnoses and treatment planning. Therefore, since MRI does not expose the body to ionized radiation and provides high-quality images, it has become a fundamental component in non-invasive diagnostic radiology for the last four decades. According to Formica and Silvestri, "Almost all of the more than 100 million MRI exams performed since early 1980 were completed without any evidence of harmful effects to the patient from the static magnetic field" (10).

[5] https://newatlas.com/medical/mri-scan-machine-learning-diagnose-alzheimers-dementia/

According to Beek et al., “There is little doubt that MRI is one of the most powerful diagnostic tools in contemporary clinical medicine, while offering highly advanced research opportunities and studies of physiological processes” (2). It is a well-organized imaging technique with the capacity of delivering high-resolution structural and functional images of human body tissues (Rao et al. 2). As mentioned above, unlike other imaging techniques (such as CT scans) that use harmful ionizing radiation, MRI uses a combination of magnetic fields and radio waves to produce high-resolution images of human body tissues. As Thorsten Dill puts it, “MRI is often described as a safe modality due to the fact that, unlike x-ray-based systems, ionizing radiation is not involved” (943). This feature of MRI along with its non-invasive nature make it a safer option for patients who require multiple scans over time or those who are pregnant.

Medical imaging, including MRI, plays a crucial role in the primary prevention, detection, monitoring, and effective treatment of various medical conditions in the modern healthcare. Therefore, equitable access to MRI services is not just a matter of convenience but a primary health right (Hilabi et al. 1). Ensuring that all patients, regardless of geographic location, socioeconomic status, or background, have the ability to undergo necessary MRI scans is essential for the early detection of diseases, accurate diagnosis, and the initiation of appropriate treatments.

Challenges Faced by Patients that Go through MRI

This subsection briefly reviews MRI-related issues that create an unpleasant experience for many patients. These issues include:

1- Long waiting lists that can delay diagnosis and treatment,

2- Appointment times that are often scheduled for late at night or early in the morning (based on my experience), which can be inconvenient and disrupt normal daily routines [6],

3- Difficulty rescheduling appointments, which considering the long waiting list for MRI, usually causes delays of a couple or more months,

4- Nervousness before and during the scan due to claustrophobia[7].

These factors are among the reasons why undergoing an MRI scan can be a stressful experience for patients. The cumulative effect of these challenges and personal anxieties can significantly impact a patient's overall healthcare journey. Addressing these issues requires an approach that includes improving scheduling systems, enhancing patient support and communication, and designing MRI facilities and procedures with patient comfort in mind. By tackling these problems, healthcare providers can greatly reduce the stress associated with MRI scans and improve the patient experience, making it more manageable and less stressful for those in need of this critical diagnostic service.

In this project, I developed an MRI scan installation with a particular emphasis on raising awareness on the problem of claustrophobia and high-noise levels that many individuals face during an MRI scan (details and photos are provided in the next chapter).

While MRI scans are safe and non-invasive, individuals with certain conditions (such as MS or Parkinson) who are required to go through regular annual MRI scans may experience nervousness or anxiety before or during the procedure. As a person with MS for 18 years who has to go through this procedure every year, I feel extra pressure during this annual process. My goal is to convey the immense pressure and stress involved in this process, which often goes unnoticed

[6] Appointment times of MRI scans might have a negative impact on quality of care and patients service (Sambeel et al. 1).

[7] Anxiety and claustrophobia are common during MRI scanning. It has been estimated that 2 million scans worldwide cannot be performed annual either due to premature termination or refusal due to claustrophobia (Munn et al. 1).

by others, including those closest to the patient. Through this work, I attempt to show the emotional state of going through MRI from abstract to representational form and how the above issue can negatively impact a patient's well-being, including delayed diagnosis, increased pain, anxiety, and healthcare costs. Recognizing this problem and emphasizing its importance can be the first step in addressing this issue in Canada.

The main challenge is to find a medium most suitable to my purpose; this contains a wide range of mediums, from traditional mediums to contemporary art disciplines, and to find a way to combine these art disciplines to achieve the desired goal. Also, to give the viewer the same sensory experience, I am simulating an MRI environment including light, temperature, noise, and, if possible, pressure. Through this simulation, I try to bridge the gap between the patient's emotional journey and the understanding of others.

By capturing the immense pressure and stress involved in the annual MRI process, I hope to shed light on the emotional state of patients and bring attention to the negative impacts it may have on an individual's well-being. The goal of simulating an MRI scan experience is to vividly portray the challenges individuals face before and during an MRI scan, aiming to raise awareness about the often-overlooked difficulties associated with this procedure. This experience will include several key issues:

- Long Waiting List: The simulation will highlight the frustratingly lengthy wait times individuals experience before accessing an MRI scan. By emphasizing this aspect, viewers can better understand patients' anticipation and the prolonged period of uncertainty they face.
- Inconvenient Appointment Times: Based on my personal experience, MRI appointments tend to be scheduled during late nights or early mornings. This

scheduling inconvenience will be highlighted in the simulation, allowing viewers to empathize with patients who must disrupt their daily routines or sacrifice sleep for medical care.

- Difficulty in Changing Appointments: Due to the lengthy waiting lists for MRI scans in Canada, rescheduling appointments often leads to extended waiting periods for several months. The simulation will emphasize the challenges patients face when trying to change their appointment times, illustrating the impact this has on their overall well-being and the negative consequences of delayed medical evaluations.
- Claustrophobia-Induced Nervousness and high noise-level: As mentioned above, anxiety and other claustrophobia-relate symptoms are common among MRI patients. The main source of anxiety comes from the need to remain lying down in the narrow gantry space during the examination. Claustrophobia is a common problem in MRI and has been defined as the combined fear of suffocation and restriction. It is estimated to occur in 2.1% to 14.3% of all MRI examinations (Iwan et al. 1326). According to Enders et al., "Patients with claustrophobic anxiety are more likely to be frightened and experience a feeling of confinement or being closed in during MR imaging" (1). In some cases, patients may not be able to even complete an MRI scan, which might increase diagnostic time and as a result delay in treatment (Lawal et al. 80). In such cases, giving patients medicine to help them relax (conscious sedation) and doing more scans (additional sequences) after they are sedated might be needed to finish the exams. According to Lawal et al., "Training MRI radiographers on how to support these patients is pertinent in

improving patients' experience. Some examples of interventions used to support claustrophobic patients in MRI are the use of mild sedation, supportive instruction, music and virtual reality" (80). As a result, these kinds of treatments increase the costs of a scan wastes valuable scanning time.

Other factors such as a concern about the examination result, high noise, vibration, isolation from the environment, or immobilization of the head during brain scans may further increase the level of anxiety in the patient (Dziuda et al. 1, Dewey et al. 3). For example, the high noise level of an MRI scan can put an individual at risk of hearing damage; to reduce this impact, MRI compliant noise cancelling headphones have been designed and produced commercially (Furlong et al. 1).

All these aspects can add up, making the experience more stressful for patients. It is important for medical staff to understand and address these concerns, providing reassurance and support to help reduce anxiety and make the MRI process as comfortable as possible for everyone involved.

The simulation of an MRI scan in this project is focused on the anxiety and nervousness experienced by patients before and during the MRI scan, particularly those affected by claustrophobia. By simulating the confined space and providing a simulated experience, viewers will gain a deeper understanding of the emotional distress patients experience during this procedure.

Long Waiting Lists

The wait times for MRI exams in Canada can vary depending on a variety of factors, including the region, the type of MRI scan needed, and the urgency of the medical condition. Figure 2 shows

the wait time for different imaging tests (including CT scan, MRI, and Ultrasound) in Canada and for different provinces during between 2020 to 2022 (Moir and Barua 9). According to Figure 2, the expected wait time for an MRI scan in Canada in 2022 was 10.6 weeks.

These long times can be concerning particularly for patients with serious or urgent medical conditions, as delays in diagnosis and treatment may lead to worsen health condition. Recently, the long wait times for MRI scans in Canada have been the subject of criticisms from patients and healthcare providers. Furthermore, these long wait times emphasize the need for healthcare system improvements to enhance capacity and efficiency, ensuring that patients can receive timely and effective diagnostic imaging services.

According to Moir and Barua, "Research has repeatedly indicated that wait times for medically necessary treatment are not benign inconveniences. Wait times can, and do, have serious consequences such as increased pain, suffering, and mental anguish. In certain instances, they can also result in poorer medical outcomes - transforming potentially reversible illnesses or injuries into chronic, irreversible conditions, or even permanent disabilities. In many instances, patients may also have to forgo their wages while they wait for treatment, resulting in an economic cost to the individuals themselves and the economy in general." (2).

	CT-Scan			MRI			Ultrasound		
	2022	2021	2020	2022	2021	2020	2022	2021	2020
British Columbia	6.8	6.0	6.0	12.0	12.0	12.0	8.0	5.0	6.0
Alberta	7.0	10.0	14.0	12.0	24.0	26.0	3.0	2.0	2.8
Saskatchewan	4.0	4.0	4.0	16.0	12.0	8.5	2.0	2.0	2.0
Manitoba	7.0	6.0	4.0	8.0	8.0	8.0	5.5	6.0	6.3
Ontario	4.0	4.0	4.0	8.0	6.0	8.0	3.0	2.0	2.0
Quebec	5.5	4.0	4.0	12.0	8.0	9.5	6.0	5.0	4.0
New Brunswick	8.0	8.0	4.5	12.0	16.0	12.0	8.0	12.0	8.0
Nova Scotia	7.0	5.5	4.0	18.0	17.5	12.0	8.0	6.0	4.0
Prince Edward Island	6.0	8.0	4.0	20.0	21.3	14.0	24.0	16.0	17.0
Newfoundland & Labrador	4.0	4.0	3.0	8.0	8.0	4.5	4.0	6.0	4.5
Canada	5.4	5.2	5.4	10.6	10.2	11.1	4.9	3.6	3.5

Source: The Fraser Institute's national waiting list survey, 2020, 2021, 2022.

Figure 2: Wait time (number of weeks) for different imaging tests in Canada and different provinces .

Late Night Appointments

Late-night appointments for MRI scans have become common in Canada due to the high demand for this service and limited resources. While these late-night appointments help more patients and optimize machine utilization, they present challenges for patients, including disruption of routines, fatigue, and limited accessibility especially for those who rely on public transportation. Additionally, these unconventional appointment times may increase anxiety for some patients, as the anticipation of a late-night scan can increase nervousness.

For example, MRI section of St. Joseph's Diagnostic Imaging Department works 24/7 except for Christmas and Boxing day[8]. Late-night scheduling can impact overall patient experience and the well-being of healthcare professionals (Alsharari et al. 1479). Recognizing and addressing these challenges is important to ensure that the scheduling of MRI scans is patient-centered, taking into consideration not only the operational efficiency but also the convenience and well-being of patients.

Strategies to address this issue involve expanding capacity, improving scheduling flexibility, and prioritizing patient comfort and convenience. Expanding capacity could mean investing in more MRI machines and hiring additional staff to operate them, allowing for a greater number of scans to be conducted within standard daytime hours. Improving scheduling flexibility involves offering a wider range of appointment times and making it easier for patients to reschedule if needed, without facing long delays for the next available slot.

Difficulty in Changing MRI Appointment Time

Several factors contribute to difficulty in changing a scheduled MRI appointment:

- Limited Availability: MRI machines are in high demand, and appointment slots are limited.
- Prioritization of Urgent Cases: Healthcare professionals prioritize patients based on medical urgency. If a patient's condition is not considered urgent, it can be more challenging to secure a new appointment time that aligns with their preferences.
- Limited Flexibility: Some healthcare facilities may have limited flexibility in accommodating appointment changes due to resource constraints, including

[8] https://unityhealth.to/areas-of-care/services/medical-and-diagnostic-imaging/

machine availability, staffing, and operating hours. This further complicates the process of changing MRI appointment times.

A study concluded that no-shows and rescheduling MRI scans lead to delay in treatment and poorer patient-care outcome (AlRowaili et al. 2). These missed appointments waste valuable scan time that could have been allocated to other patients, which as a result increase wait times and delaying diagnoses (Marbouh et al. 509, Glauser 149). Furthermore, when patients reschedule their MRI scans, the delay in obtaining diagnostic information directly impacts timely medical decision-making, potentially affecting the course of treatment and its effectiveness. By addressing the challenges related to changing MRI appointment times, patients can have greater flexibility and control over their healthcare schedules, leading to improved patient satisfaction and overall healthcare experience. This enhanced flexibility enables patients to better balance their health needs with their personal and professional responsibilities, reducing the stress and inconvenience associated with healthcare appointments. When patients feel that their time and needs are respected, it leads to a positive relationship between healthcare providers and patients, enhancing trust and communication. Additionally, improved scheduling systems that accommodate patient preferences can lead to more efficient use of MRI resources, reducing no-shows and last-minute cancellations. This not only benefits patients directly but also contributes to the smoother operation of healthcare facilities, allowing them to serve more patients effectively and efficiently.

Nervousness Before and During the Scan due to Claustrophobia

Many individuals experience nervousness and anxiety before and during MRI scans due to claustrophobia. Claustrophobia is the fear of enclosed or confined spaces, and the tight, enclosed environment of an MRI machine can trigger intense feelings of discomfort. Patients with

claustrophobia may struggle with feelings of panic, unease, and a sense of being trapped during the scan, which can impact their overall experience and cooperation[9]. To address this issue, healthcare providers can adopt several strategies to help alleviate these fears and make the experience more comfortable. These include offering detailed pre-scan counseling to explain the process and what to expect, using open or wide-bore MRI machines that feel less confining, providing headphones with music or earplugs to reduce the noise of the machine, and allowing a friend or family member to be present for reassurance. Additionally, some facilities may offer sedation options for those who are extremely anxious, helping them to remain calm during the scan.

Measuring Wait Times

Timely access to MRI scan is crucial for quick diagnosis, monitoring, and treatment of a wide range of medical conditions (Bor et al. 2). In Canada, like in many other countries, there can be long wait times for patients to undergo MRI exams due to the high demand for this service (Emery et al. 1, Bartsch et al. 2). These delays can have significant negative impact for patient health, including long periods of uncertainty, delayed start of necessary treatments, and potential worsening of medical conditions that require immediate attention.

[9] https://www.santaclaritamri.com/content/claustrophobia-and-mris and https://queensquare.com/article/mri-and-claustrophobia/

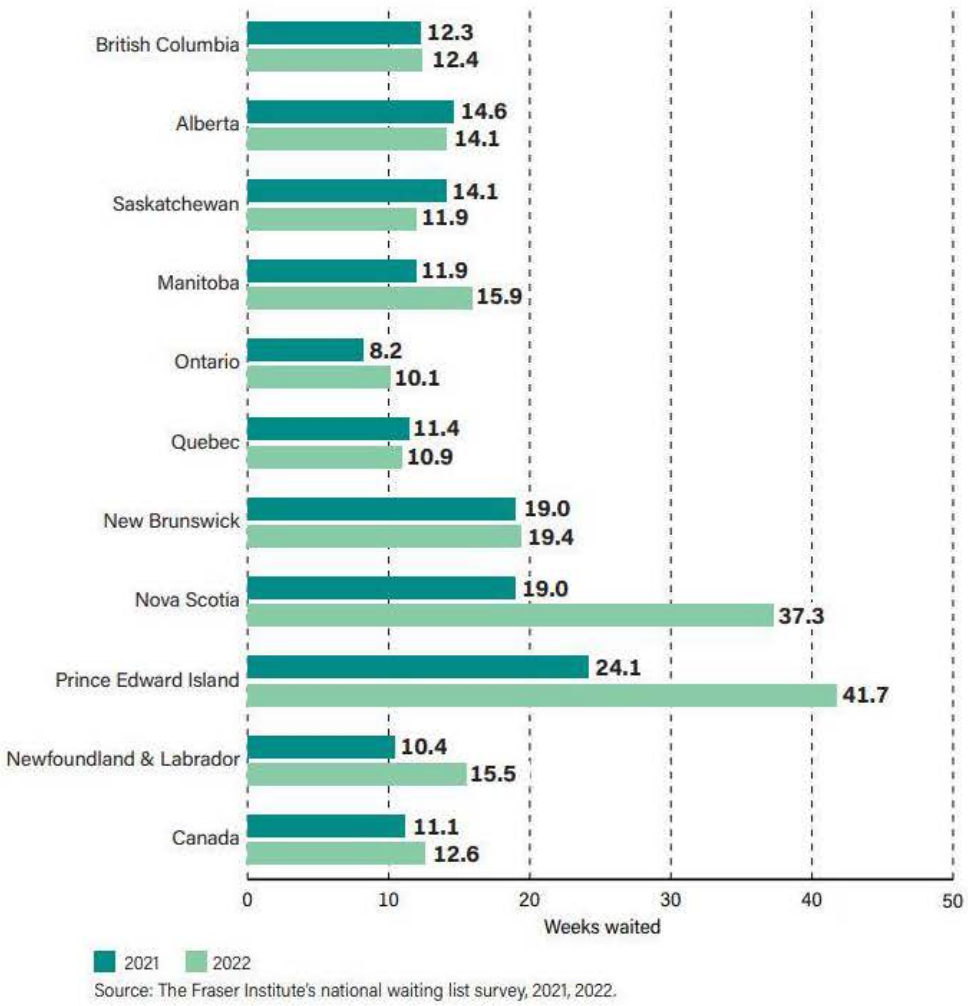


Figure 3: Wait time by province in 2021 and 2022- Weeks waited from referral by GP to appointment with specialist.

The total wait time to receive a medical imaging can be broken into the following two consecutive segments:

- Wait 1: That is from referral by a general practitioner to consultation with a specialist,
- Wait 2: That is from the consultation with a specialist to point at which patient receives treatment.

Increase in each segment contributes to an increase in the total wait time. According to The Fraser Institute, waiting time in the first segment (i.e., from referral by a general practitioner to

consultation with a specialist) has risen from 11.1 weeks in 2021 to 12.6 weeks in 2022. The waiting time in the second segment (i.e., from consultation with a specialist to the point at which the patient receives treatment) has increased from 14.5 weeks in 2021 to 14.8 weeks in 2022 (Moir and Barua 2). Figure 3 and Figure 4 compare provincial wait times (i.e., wait time 1 and wait time 2) in 2021 and 2022.

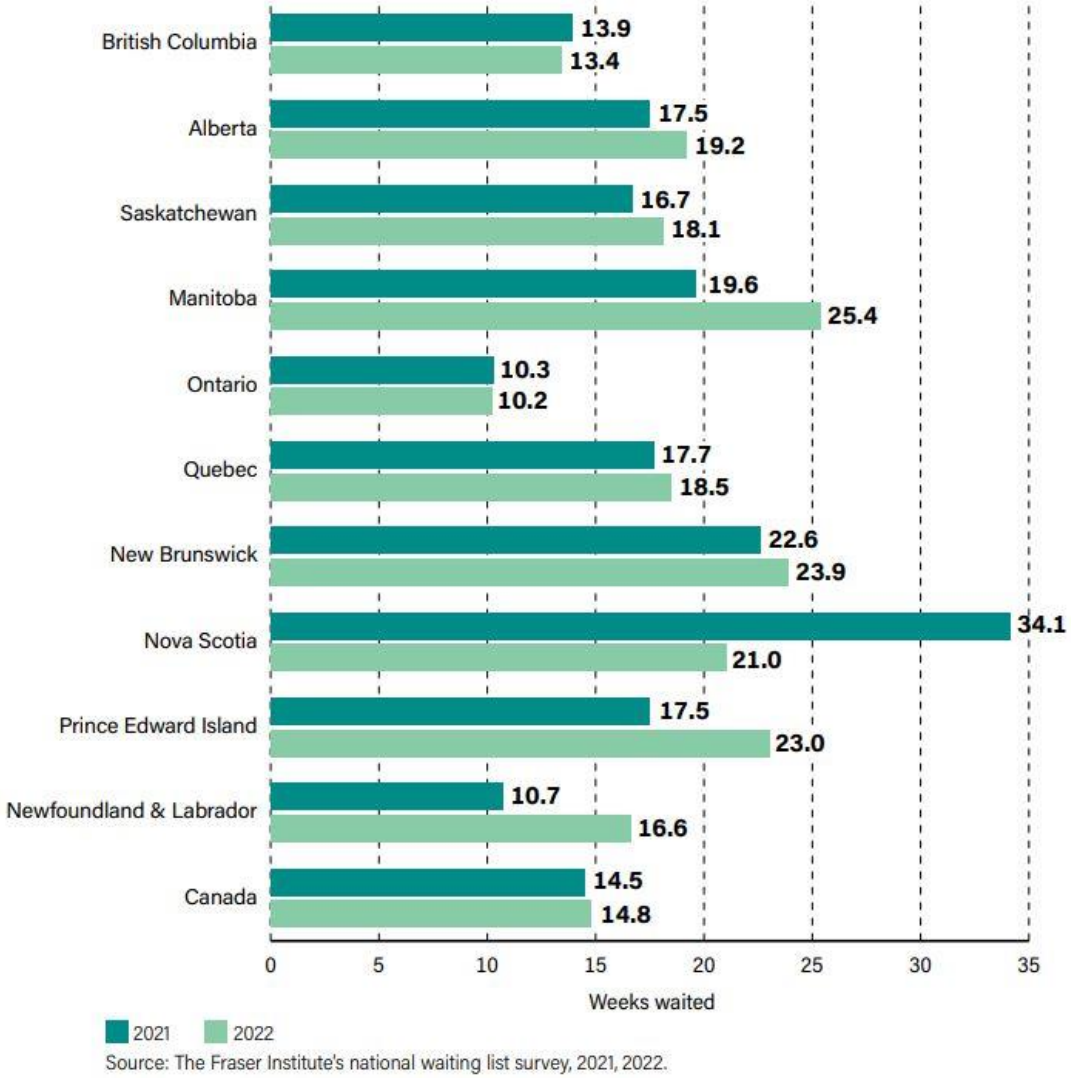


Figure 4: Wait time by province in 2021 and 2022- Weeks waited from appointment with specialist to treatment.

The wait times for MRI exams in Canada can vary depending on a variety of factors, including the region, the type of MRI scan needed, and the urgency of the medical condition. According to the Fraser Institute, the expected wait time for an MRI scan in Canada in 2022 was 10.6 weeks[10], which is slightly longer that the previous year's wait time of 10.2 week. These long wait times can be concerning especially for patients with serious or urgent medical condition, as delays in diagnosis and treatment may lead to worsen health condition. In the Fraser Institute 2022 report on wait time for health care in Canada, it is maintained that "wait times can, and do, have serious consequences such as increased pain, suffering, and mental anguish. In certain instances, they can also result in poorer medical outcomes transforming potentially reversible illnesses or injuries into chronic, irreversible conditions, or even permanent disabilities." (Moir and Barua 2). Note that in this context, the MRI wait time is measured from the date an MRI request is received until the date the MRI is performed (i.e., wait 2). This does not include the wait time to receive a referral from a physician to visit a specialist, and then receive the request for MRI from the specialist (i.e., wait 1). Figure 5 displays these two wait times and shows which one is used to measure MRI wait times.

Figure 5:Measuring MRI wait time [11]

[10] https://www.fraserinstitute.org/sites/default/files/waiting-your-turn-2022.pdf
[11] https://www.princeedwardisland.ca/en/information/health-pei/magnetic-resonance-imaging-mri-wait-times

Criticism in of Long Waiting Time in the Mainstream Media

Recently, the long wait times for MRI scans in Canada have been subject of criticisms from patients and healthcare providers[12]. Media reports often feature personal stories from patients who have faced delays in receiving essential diagnostic tests. Even in a recently released public opinion poll, it is stated the Canadians want the Federal government to take an active role in reducing wait time for medical imaging[13]. As the patient advocate Claire Snyman puts it[14], "As an individual diagnosed with a brain tumor, MRIs and CT scans were a regular part of my care to help monitor my condition. When my brain tumor doubled in size, I became very ill and with limited access to medical imaging, I had to look for alternative ways to access imaging external to my provincial healthcare system, which saved my life. Not all patients are in a position to access privately funded services, nor should they have to. Timely access to quality medical imaging should be a right for Canadians and needs to be a priority for government".

The growing demand for quicker access reflects a broader concern about the efficiency of the healthcare system and its ability to meet patients' needs promptly. The long wait times have caused considerable distress and inconvenience for patients, who in some cases waited for months to access this diagnostic service. The high demand for MRI scan in Canada, coupled with limited resources, has resulted in a backlog of patients waiting for their turn, which has caused the efficiency and effectiveness of the Canadian healthcare system to be questioned[15]. As Emery et al.

[12] https://ottawa.citynews.ca/local-news/canadian-radiologists-sound-the-alarm-on-long-wait-times-for-ct-scans-mris-6133149
https://globalnews.ca/news/8505265/medical-imaging-backlogs-canadian-hospitals/

[13] https://www.newswire.ca/news-releases/newly-released-public-opinion-poll-states-canadians-want-the-federal-government-to-take-an-active-role-in-reducing-wait-times-for-medical-imaging-822597947.html

[14] https://www.newswire.ca/news-releases/newly-released-public-opinion-poll-states-canadians-want-the-federal-government-to-take-an-active-role-in-reducing-wait-times-for-medical-imaging-822597947.html

[15] It is important to note that the length of wait times does not solely determine the overall effectiveness of the Canadian healthcare system.

conclude, “The greatest contributors to testing delays relate to when and where a test was ordered. Wait times affect length-of-stay and the quality of patient care” (77).

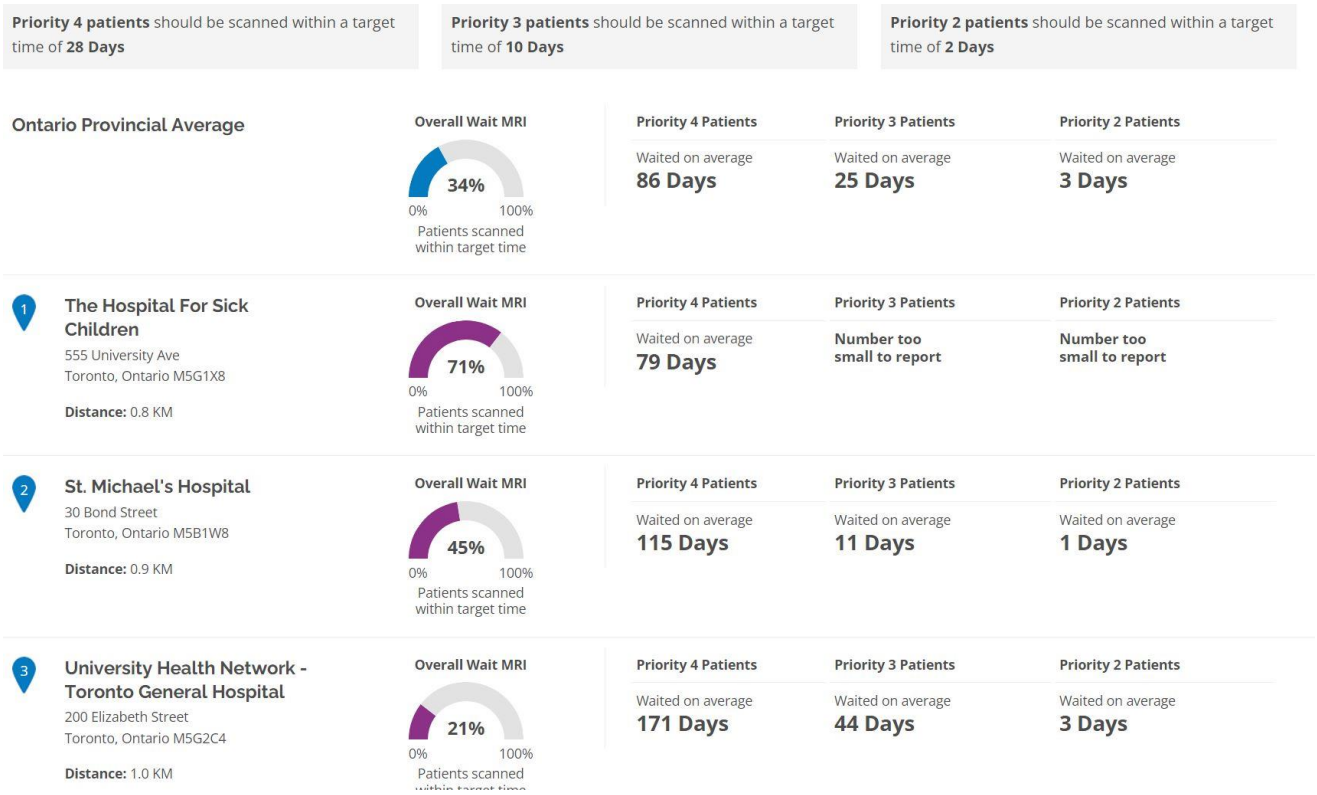


Figure 6: Overall MRI wait time in Ontario and 3 major hospitals in Toronto based on patient priority (reporting period December 2023)[16]

Statistics on MRI Wait Times in Toronto

In Toronto, MRI wait times depend on patient prioritization. To promote the best overall health outcomes, healthcare providers divide patients into four categories depending on need as follows[17]:

- Priority 1 patients are emergencies. They are seen immediately,
- Priority 2 patients should be seen within 2 days,
- Priority 3 patients should get their scans within 10 days,
- Priority 4 patients should be seen within 28 days.

[16] Generated using the following website https://www.ontariohealth.ca/public-reporting/wait-times
[17] https://www.pockethealth.com/2023/09/19/mri-scan-toronto/

Ontario Health maintains a website[18] that tracks wait times for diagnostic imaging in the province. Toronto, MRI wait times, which depend on the availability of both MRI machines and skilled technologists to operate them, can range widely. Figure 6 is generated using Ontario Health website[19] data on diagnostic imaging wait times (CT and MRI) based on December 2023 data and compares the overall MRI wait time in Ontario and three major hospitals in Ontario according to the patient priority. It should be noted that patients with emergency conditions (i.e., Priority 1) are seen immediately and are not included in wait times data. Next, a quantitative analysis using the raw data obtained from Canadian Institute for Health Information is provided.

Quantitative Analyses of Wait time in Canada using Raw data from CIHI

Raw data for provincial MRI wait times were obtained from the Canadian Institute for Health Information (CIHI). CIHI is an independent, not-for-profit organization that provides essential information on Canada's health system and the health of Canadians[20]. Wait time information[21] by CIHI consists of a wide range of procedures, including hip and knee replacement, CT scan, MRI scan, Radiation therapy, etc. for different Canadian provinces[22]. Since the focus of this research is MRI wait times, other procedures were filtered out. To have a comprehensive visualization, the most recent ten years of data for each province is used, starting from 2013 to 2022. The following definitions have been applied in reporting the MRI wait times:

[18] https://www.ontariohealth.ca/public-reporting/wait-times
[19] https://www.ontariohealth.ca/public-reporting/wait-times
[20] https://www.cihi.ca/en/about-cihi
[21] Canadian Institute for Health Information. Wait Times for MRI Scan [indicator]. Accessed October 22, 2023. https://www.cihi.ca/en/indicators/wait-times-for-mri-scan
[22] The raw data is freely available to public and can be downloaded as an Excel file from CIHI's website.

- Wait time: The number of days a patient waited, from the date the order for the scan was received to the date that the patient received an MRI scan. The wait time is calculated as the difference between the finish date and start date, which are defined as follows:
    - Start date: Waiting for a health service begins with the booking of a service, which is when the patient and the appropriate physician agree to a service, and the patient is ready to receive it,
    - Finish date: Waiting for a service end when the patient receives the service.
- Time frame: The data for each year contains information for the first two quarters of the fiscal year (i.e., April 1st to September 30th). It is believed that this 6-month period is a good representative of the full year. The selected data range for this study is between 2013 to 2022.
- Population:
    - Includes all patients aged 18 and older.
    - Includes all diagnostic scans, includes priority levels, excludes routine follow-up scans, and excludes mammography screening and prenatal screening.
    - Includes data for the following Canadian provinces: Alberta, Manitoba, Prince Edward Island, Nova Scotia, Ontario, Saskatchewan, and British Colombia. It should be noted that 2014 data for Saskatchewan was missing in the original data that we estimated using interpolation between 2013 and 2015 data. Furthermore, for British Colombia MRI wait data was available

for the most recent five years (i.e., 2018 to 2022), so the visualization for this province is only limited to those five years.

- The original data set includes all nine provinces. However, the following provinces were excluded from our visualization:
  - ✓ Quebec: No data for median, 90th percentile, the number of scans for MRI scans between 2013 to 2022 is recorded.
  - ✓ Newfoundland: No data for median and 90th percentile for MRI scans between 2013 to 2022 is recorded.

The following measures are used for MRI scan wait times:

- Median (or 50th percentile): Number of days that half (50%) of patients waited before receiving MRI scans.
- 90th percentile: Number of days that 1 out of 10 patients waited before receiving MRI scans.
- Volume: The number of MRI scans in the first two fiscal quarters (i.e., April 1st to September 30th).

For example, the median and 90th percentile for Ontario province in 2020 is 26 and 173 days, respectively. Here the 90th percentile represents an extreme case, indicating that 10% of patients receive care after waiting 173 days. The total number MRIs in the first two fiscal quarters, in this province, in the same year was 246,448. This implies that 123,224 patients (half of the patients) waited at least 26 days before receiving the MRI scan. Also, 24,645 (10 per cent of patients) waited at least 173 days (or longer) to receive an MRI scan. Table 1 summarizes the clean/processed data used in my analyses. I calculated statistics (including mean and standard deviation) for the median, 90th percentile, and volume for each of the six provinces.

Table 2 summarizes the statistics for each province. From Table 2, it can be observed that the province of Ontario on average has the highest number of MRI scans each year (329,409 MRI scans on average); half of such cases wait 31 days or longer to receive the service which implies that the other half receives service within the first 31 days). The province of Manitoba has the longest median wait time (on average), such that half of the patients (29,335 patients on average) wait at least 80 days to receive the service. Finally, from Table 2 it can be observed that Alberta has the longest 90th percentile wait time (on average), which means 10 per cent of patients (~6,189 patients on average) waited 215 days or longer to receive the service. Note that the standard deviation is calculated for each case to show how scattered the data is around the calculated mean value (i.e., a smaller standard deviation indicates the values tend to be close to the mean, and vice versa).

Table 1: MRI wait time data between 2013 to 2022 for six Canadian provinces.

	Alberta			**Manitoba**			**Prince Edward Island**		
Year	**50th**	**90th**	**Volume**	**50th**	**90th**	**Volume**	**50th**	**90th**	**Volume**
2013	80	247	55,288	70	127	23,848	58	135	2,092
2014	60	214	61,371	82	167	26,505	71	172	1,857
2015	90	172	60,651	99	189	21,277	56	167	1,748
2016	85	242	59,916	110	196	26,183	52	181	1,911
2017	95	277	60,247	76	219	33,945	80.3	231.4	2,645
2018	77	279	61,701	56	156	38,745	40.2	126.6	2,441
2019	72	296	65,309	55	133	37,810	45.3	210	2,253
2020	85	343	56,066	83	204	27,630	35.2	234.1	2,368
2021	45	255	73,208	66	220	38,298	34.2	214.4	2,405
2022	46	189	65,111	99	174	19,312	41.2	290.7	2,102
	Nova Scotia			**Ontario**			**Saskatchewan**		

	Alberta			Manitoba			Prince Edward Island		
Year	50th	90th	Volume	50th	90th	Volume	50th	90th	Volume
Year	50th	90th	Volume	50th	90th	Volume	50th	90th	Volume
2013	44	137	9,109	23	60	291,633	28	88	12,100
2014	58	169	10,427	29	73	299,918	30	120	11,842
2015	55	202	10,319	36	91	306,561	32	152	11,584
2016	57	203	11,099	33	99	347,657	48	212	11,459
2017	48	241	12,469	35	96	355,639	34	181	12,148
2018	57	237	13,101	35	96	360,689	33	189	12,305
2019	50	251	13,242	35	114	356,584	48	260	12,044
2020	37	287	7,683	26	173	246,448	31	228	8,665
2021	83	263	12,044	29	111	358,935	30	193	12,638
2022	91	348	12,679	33	151	370,029	49	181	11,707

Table 2: Statistics (mean and standard deviation) for MRI wait time in six Canadian provinces

Province/Statistics	Mean (average)			Standard deviation		
	50th	90th	Volume	50th	90th	Volume
Alberta	74	251	61,887	18	51	5,122
Manitoba	80	179	29,355	19	33	7,290
Prince Edward Island	51	196	2,182	15	50	289
Nova Scotia	58	234	11,217	17	60	1,838
Ontario	31	106	329,409	4	34	40,772
Saskatchewan	36	180	11,649	8	50	1,106

Multiple Sclerosis (MS)

MS is the most common disabling neurologic disease among young people, with approximately one million cases in north America. MS is a hidden disease; as David Whelan puts it, “Despite the

diagnosis, it remains an enigma: symptoms shift undetected beneath the surface like water molecules held in an opaque balloon" (3). Each individual's experience with MS is unique, and the perception of the disease is also different for each person depending on the stage of MS, lifestyle, and prior health conditions. However, MS commonly involves challenges in cognitive, emotional, motor, and sensory functions, as a result of a person's immune system attacking their brain and spinal cord (Price et al. 2048).

Patients with MS are particularly challenged not only by the burden of their condition but also by the additional stress of enduring long wait times for their annual MRI scans. As Madl puts it, "Despite being noninvasive and painless, MRI is recurrently associated with stress and anxiety in patients. This adversely affects patient experience and may be associated with negative outcomes for the health care provider" (423). While MRI scans are a crucial part of disease management, they can be a significant source of stress due to the time-consuming and uncomfortable process, as well as the fear of potential bad news. According to Madl et al., "MRI-related anxiety is present in 30% of patients and may evoke motion artifacts/failed scans, which impair clinical efficiency" (841). Consequently, the adverse effect of anxiety and stress triggered by MRI procedure in patient with MS may lead to scan repetition (due to motion artifacts in images), premature terminations, and/or longer scan duration, which in turn causes more anxiety. Andre et al. estimated that the average cost per scanner per year due to unexpected patient behavior is approximately $115,000. This cost is at least partially attributed to patient anxiety (Andre et al. 694, Madl et al. 841).

Claustrophobic Patients

As mentioned above, the enclosed space of the MRI machine can provoke claustrophobia in some patients, further escalating their stress and anxiety levels during the scan. Claustrophobia is the fear of enclosed spaces that is a widespread problem experienced during MRI scans. Claustrophobia, in this context, can be defined as the combined fear of suffocation and restriction due to the confined space of the MRI machine. It is common among claustrophobic patients to be frightened and experience a confinement or being trapped without a way-out during MR imaging.

Figure 7: An Open MRI machine[23]

The common type of MRI machine is the closed MRI machine, which is used more often than open types because it provides higher-quality images. A closed MRI machine has a tube-like tunnel that the patient enters in order to get the images needed. This is the original shape of the MRI machine. A closed MRI will typically range from a 1 tesla to 3 tesla. Figure 7 and Figure 8 show an open MRI and a modern 3 tesla closed tunnel MRI machine, respectively. The closed

[23] https://www.dmcprimarycare.com/blog/2018/04/05/traditional-vs-open-mri-4-things-you-should-know/

tunnel type of MRI machines is preferred over open type when greater details in images are required, which is the case for people with MS since high quality MRI images are needed for diagnostic or monitoring purposes (given that Open MRIs do not provide the best images for detecting MS activity[24]).

Figure 8: Modern 3 tesla clinical MRI scanner[25].

The challenge of balancing the need for high-quality imaging with patient comfort highlights the ongoing efforts in the medical community to innovate and improve MRI technology. This includes the development of new MRI designs that aim to reduce the claustrophobic experience while maintaining image quality and exploring alternative imaging techniques that could provide viable options for patients with severe claustrophobia. Addressing these concerns is

[24] https://www.nationalmssociety.org/Symptoms-Diagnosis/Diagnosing-Tools/MRI
[25] https://en.m.wikipedia.org/wiki/File:Modern_3T_MRI.JPG

crucial for ensuring that all patients can undergo necessary diagnostic imaging in a manner that minimizes stress and maximizes safety and comfort.

Figure 9 shows the extent to which an individual with MS must be moved inside a closed MRI scan. From Figure 9, it can be observed that the confined space of the tunnel along with the requirement for a significant portion of the body to be inside can lead to feelings of anxiety and stress for individuals who are claustrophobic.

This claustrophobic reaction not only exacerbates patient discomfort but also increases the likelihood of scan complications, thereby impacting the overall diagnostic process. According to Enders et al., "prevention of MR imaging by claustrophobia is a common problem and approximately 2,000,000 MRI procedures worldwide cannot be completed due to this situation. Patients with claustrophobic anxiety are more likely to be frightened and experience a feeling of confinement or being closed in during MR imaging" (1).

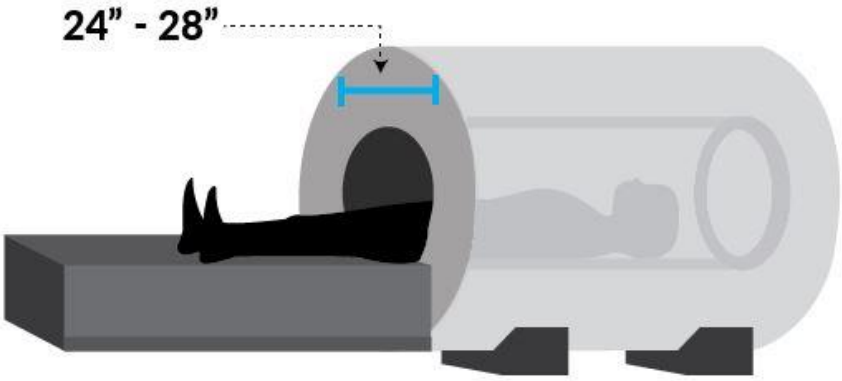


Figure 9: Closed Tunnel-style MRI machine[26]

[26] https://www.encinoopenmri.com/claustrophobia-mri/

Duration and Sound Level

Undergoing MRI scans is a lengthy process that is difficult for many patients, with elderly people often facing greater challenges during this process. Patients are required to remain still for an extended period of time in a scanner that features a comparatively narrow bore, while being exposed to noise-like sound that its level can reach up to 130.7 decibels[27] (Oztek et al. 181). This intensity of sound is generated by the rapid switching of the MRI machine's gradient magnets during the imaging process, which is necessary for creating detailed images of the body's internal structures. Given these high noise levels, patients with MS who are going through an MRI scan are usually required to wear ear protection, such as earplugs or noise-canceling headphones, to mitigate the risk of hearing damage. This precaution is essential not only for comfort but also to protect the auditory health of patients during this procedure, given that in some cases the patient must remain still within the narrow tunnel for up to two hours. Although, some newer MRI models are designed to operate more quietly, regardless of advancements, the priority remains on ensuring the patient's safety and minimizing their discomfort during the imaging process. As referenced on the level of MRI sound, Table 3 provides a comparison between MRI sound and common loud noises measure at decibel levels. As a result, the overall process becomes an unpleasant experience for many patients that can even lead to premature termination or low quality of images (which would require repeating the scan).

[27] For comparison, a plane taking off would reach 120 dB. https://www.grupooneair.com/aircraft-noise-acoustic-pollution/

Table 3 Comparison between MRI sound level and other noisy activities[28]

#	Activity	Sound level (dB)
1	Alarm clock	70 decibels
2	Vacuum cleaner	70 decibels
3	Food Processor or blender	94 decibels
4	Rock concert	112 decibels
5	Chainsaw	112 decibels
6	Jet planes take off	120 decibels
7	Construction jackhammer	130 decibels
8	MRI sound	130.7 decibels

To address this issue, it is proposed that healthcare providers consider changes to the design of MRI machines (Stoja et al. 2, Alarifi et al. 712, Oztek et al. 185) and manage waiting lists for MRI scans (Emery et al. 10). One way to make MRI scans more comfortable and less stressful for patients is by updating the design of MRI machines to be more patient friendly. For example, noise levels may negatively affect the performance of MRI (Moelker and Pattynama 123), which in turn can negatively influence neural responses in the image (Peelle 4). Making MRI scans patient-friendly may include reducing the noise levels, improving the comfort of the scan bed, and increasing the amount of space in the scanning area.

Art as an Effective Language to Articulate Pain

Given that the pain and the stress experienced by individuals with MS are often hidden, patients often find it challenging to articulate their experience with MRI process using words. In such situations, art can be considered as an effective language to articulate pain in the absence of words.

[28] https://www.envrad.com/noises-to-expect-during-an-mri/#:~:text=MRI%20noises%20can%20range%20anywhere,Alarm%20clock%20or%20vacuum%20cleaner

Research shows that visual representations of stress and suffering can be more successful than text-based media as a means of communication because art is a universal language and can be widely understood by the general public (Raine 2016, Bending 2006). It is argued by researchers that art can move beyond its traditional uses as a mean for self-expression, therapy, and empowerment to become a highly efficient tool for communicating the corporeal and emotional feelings of people rendered speechless by anxiety (Cohen 2000, LaCapra 1999).

In this project, my goal is to show the amount of stress and anxiety that I endure before and during my annual MRI scans through art. Through my artwork, I share my own personal experience (autoethnography research approach) as a person who has lived with MS for 18 years and has had to go through MRI scan at least once a year. I hope to show how MRI related issues can have a negative impact on patient's well-being, including delayed diagnosis, increased pain, increased anxiety, and increased healthcare costs. Recognizing this problem and emphasizing on its importance can be the first step in addressing this issue in Canada.

Small Size Prototype of an MRI Device

The journey to reaching the MRI appointment will likely be an ordeal, inducing discomfort even in individuals unaffected by claustrophobia. Despite the fact that this test carries the least amount of risk, as discussed before, its unfavorable psychological repercussions cannot be disregarded.

As a prototype, I created a small model of an MRI device. I used fences for the body of this model, which makes it resemble a cage. Certain sections of this model's body are covered with MRI scan images of the brain and spinal cord. As a consequence of light radiation from the bottom of the model, shadows of brain images are projected onto the walls and ceiling, creating an immersive environment. The choice of materials and the incorporation of actual MRI images

serve as a powerful metaphor for the introspective journey patients undergo during medical imaging procedures.

The construction of this model required meticulous planning and execution, as detailed in the SketchUp. The software enabled me to explore various structural configurations and to visualize how light interacts with the model's surfaces before the physical creation began. This preparatory phase was crucial in addressing potential challenges and in ensuring the accuracy and effectiveness of the light projection. Figure 10, Figure 11, and Figure 12 show the MRI device prototype designed in SketchUp, which I used to figure out the details of the model.

Furthermore, the inclusion of Figures 10 to 12 in the documentation provides a comprehensive understanding of the design process, from conceptual sketches to detailed blueprints. Figure 12, on the other hand, captures the essence of the completed prototype, highlighting the interplay of light and shadow that defines this unique installation. This visual representation is key to appreciating the depth and impact of the project, offering viewers a glimpse into the innovative melding of medical technology with artistic expression.

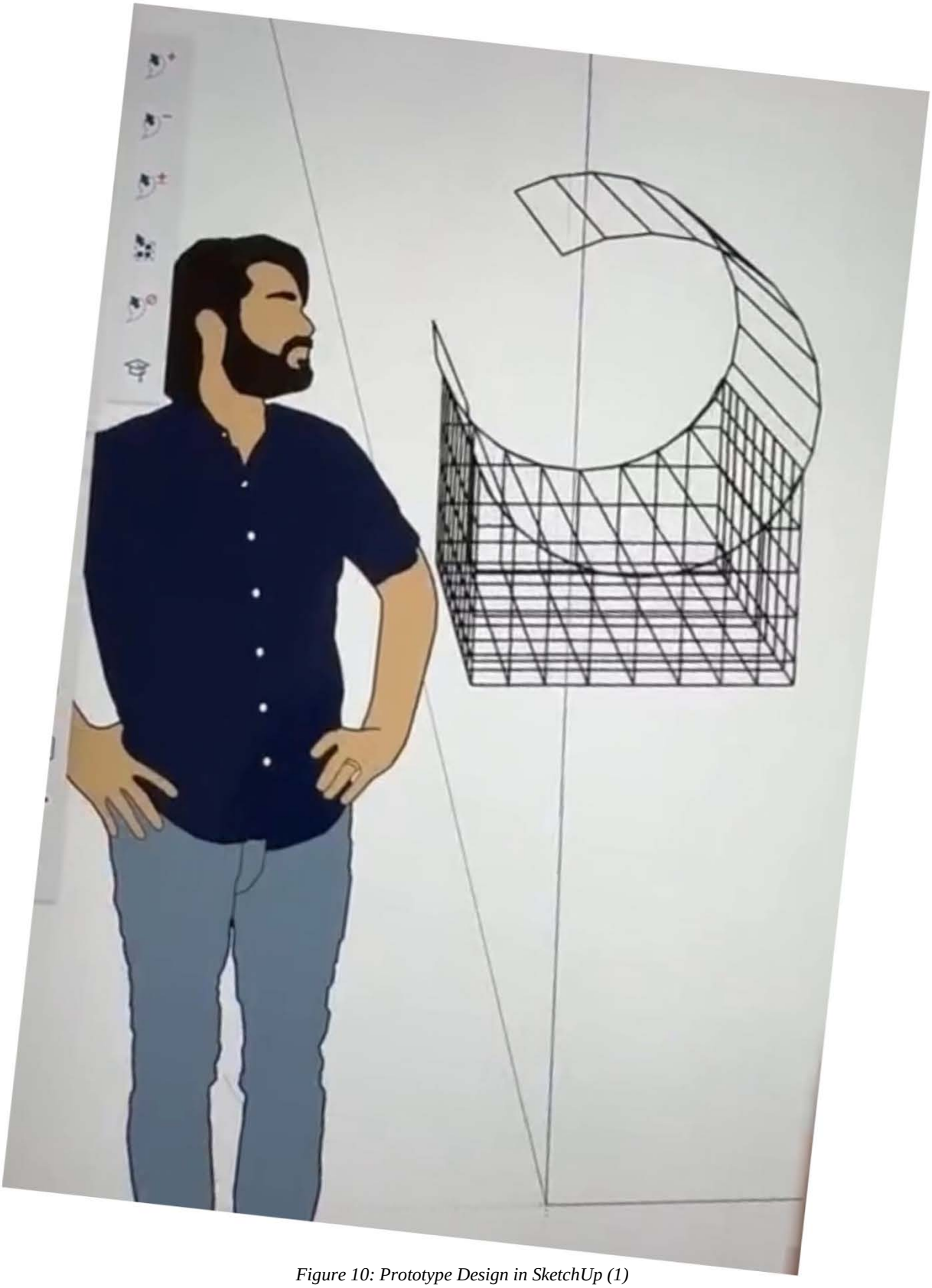


Figure 10: Prototype Design in SketchUp (1)

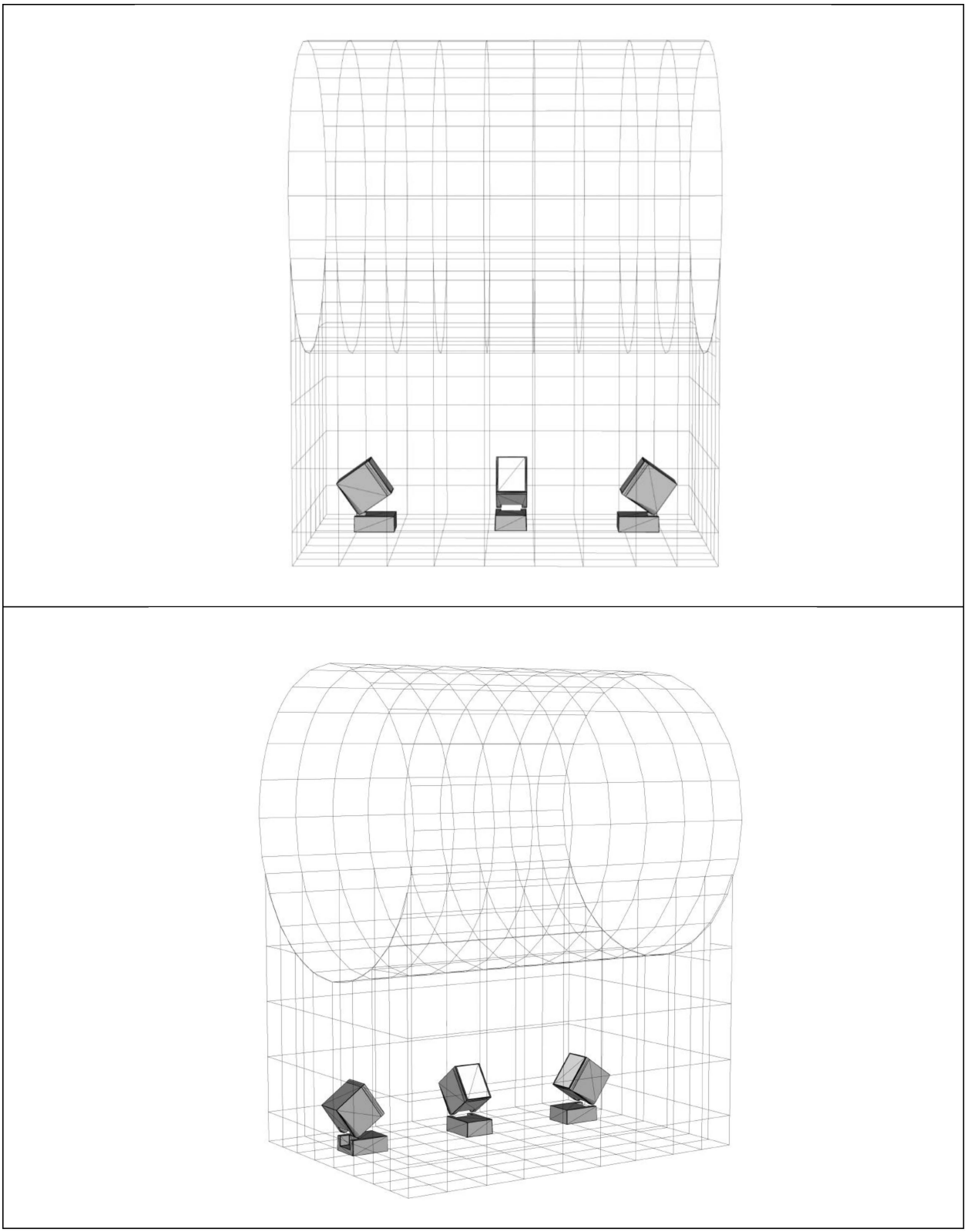


Figure 11: Prototype Design in SketchUp (2)

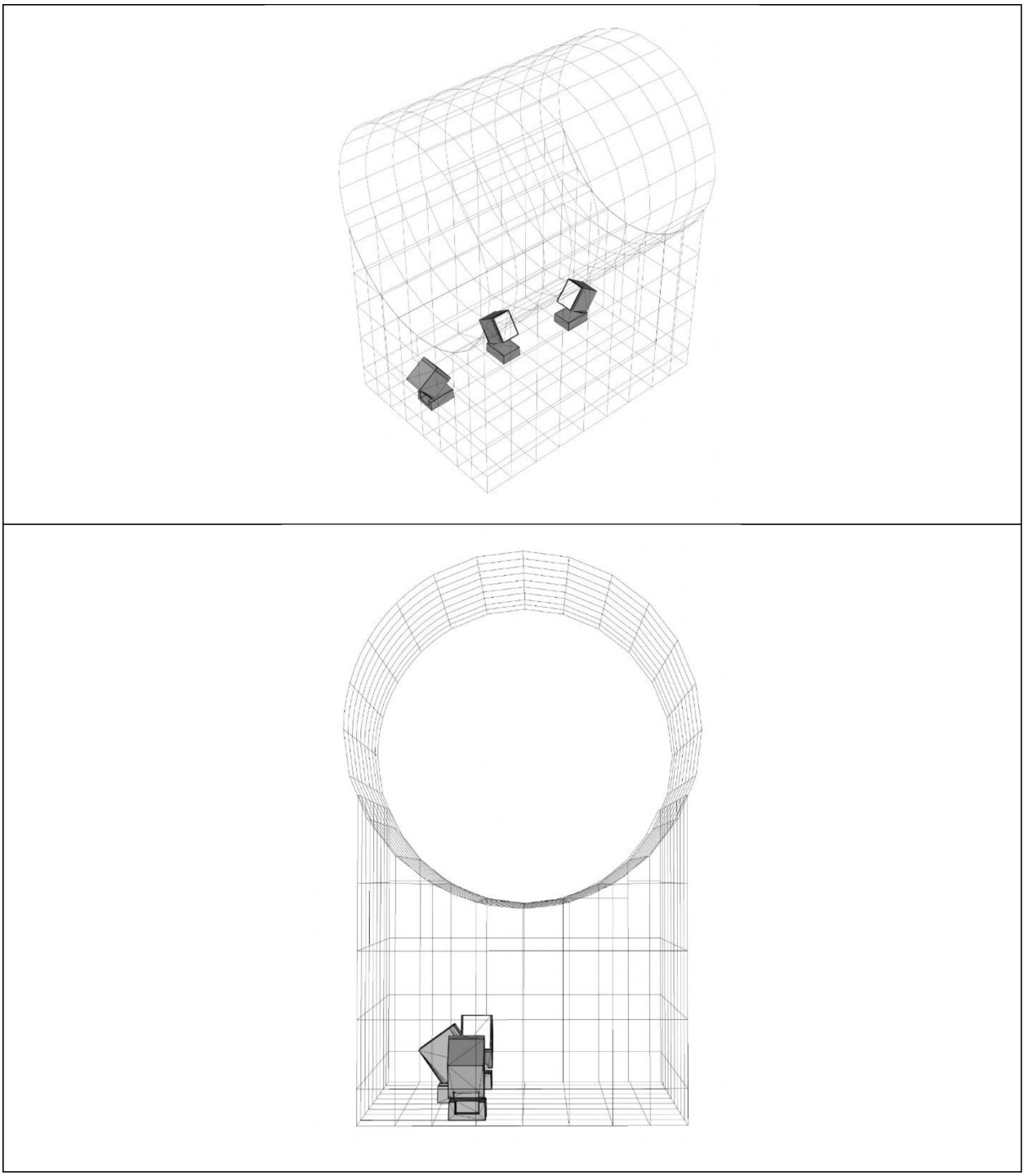


Figure 12: Prototype Design in SketchUp (3)

Figure 13 shows a prototype of the initial version of the model along with the impact of light and shadows. Building this small version of the MRI device prototype was a strategic step taken before embarking on the construction of a larger, more complex version. This preliminary model served as a critical test bed for identifying weaknesses and potential areas for improvement in the design and execution. By scaling down, I was able to experiment with different materials, such as the fences used for the body, and to assess their viability, durability, and visual effect in simulating the intricate structure of an MRI machine.

The inclusion of MRI scan images on parts of the model's body and the innovative use of light to project these images onto surrounding surfaces were key features that underwent rigorous testing in this smaller scale. This process allowed me to observe firsthand how variations in light intensity and angle could dramatically alter the ambiance of the space, influencing the overall impact of the installation. Such insights were invaluable in refining the concept, ensuring that the larger version would not only replicate these effects on a grander scale but also enhance them for greater immersive experience.

Moreover, the challenges encountered during the construction of this prototype, such as ensuring the stability of the structure and the precise alignment of light sources for optimal shadow projection, provided essential lessons. These experiences informed the development process of the larger model, guiding adjustments in material choices, structural support, and lighting techniques to avoid similar pitfalls.

The mixture of MRI images within the model not only showcases the beauty of medical imaging but also offers viewers a unique experience that bridges the gap between science and art. The juxtaposition of clinical imaging within an artistic framework contributes to a deeper

understanding of both medical visualization and creative expression, thereby enriching the realms of both healthcare and artistic exploration.

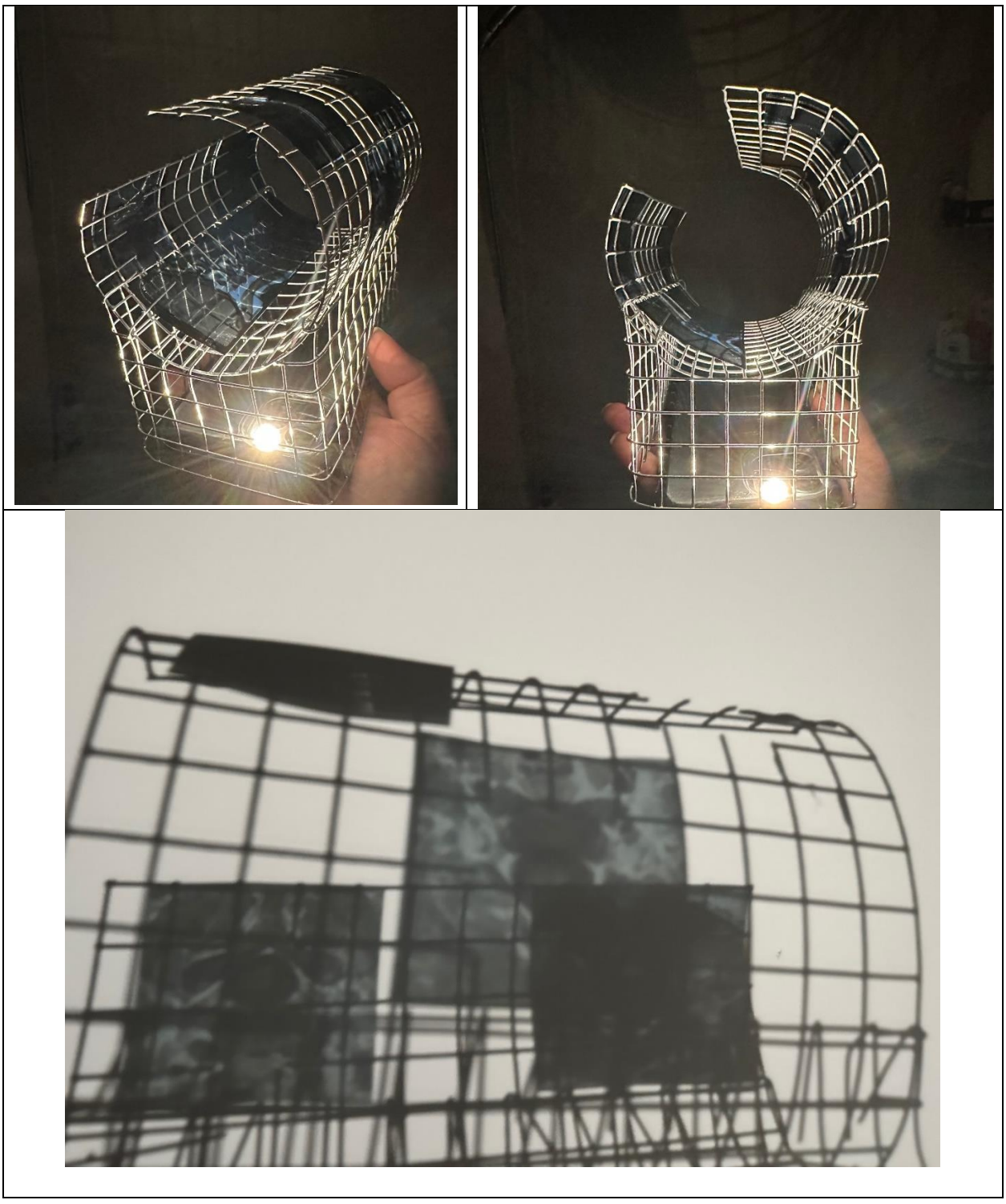


Figure 13: Small MRI prototype design, before starting the work on the larger version

Figure 14 shows materials selected for constructing the larger version of the MRI device model. This carefully curated selection represents an evolution of the project, building upon the insights gained from the initial prototype.

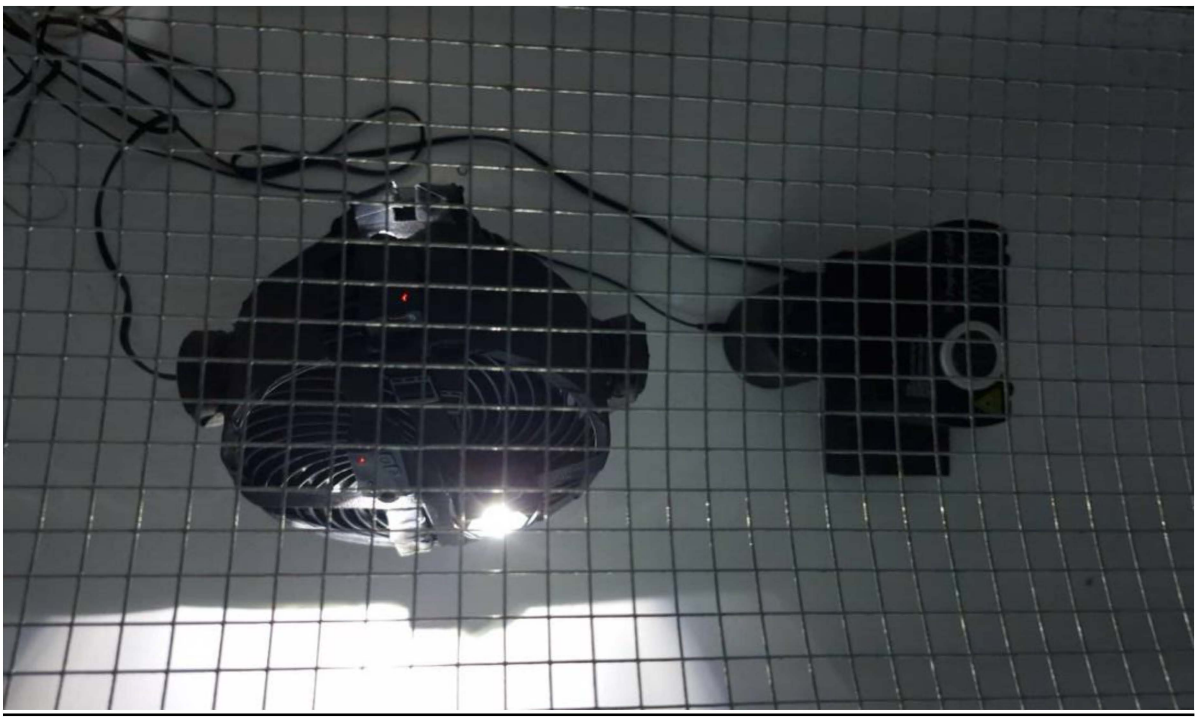


Figure 14: Materials that are used to build the large-scale MRI device.

The next series of figures (Figure 15 to Figure 23) take a pivotal turn, focusing on my experimentation with light and detailing the step-by-step process of constructing the larger version of the MRI device model. These figures serve as a visual diary, capturing the evolution of the project from conceptual sketches to the tangible, intricate assembly of materials and technology.

In this visual narrative, the initial frames reveal the experimental setups where various lighting techniques are tested. These tests are crucial for determining how different light sources, intensities, and colors interact with the selected materials, influencing the ambiance and the projection of MRI images within the installation space. This phase of experimentation is key to achieving the desired visual effects, ensuring that the light not only enhances the aesthetics of the model but also serves as a medium for storytelling and immersion.

After the extensive experimentation phase, several key changes were made compared to the prototype to address the insights and challenges uncovered. These modifications were crucial in enhancing the functionality, aesthetic appeal, and overall impact of the larger MRI device model. For example, the framed MRI images first installed on outside of the body of the MRI device (see Figure 17 and Figure 18), but later I decided to hang them to achieve a better and more aesthetic lighting impact (see Figure 21 and Figure 22).

These changes were the culmination of careful consideration of the prototype's performance and the project's objectives. They reflected a commitment to excellence, pushing the boundaries of what was technically and creatively possible. By adapting and evolving the model based on experimentation, the project moved closer to its goal of offering an engaging, enlightening, and visually stunning exploration of an MRI experiment.

Figure 15: The process of building the model – Number 1

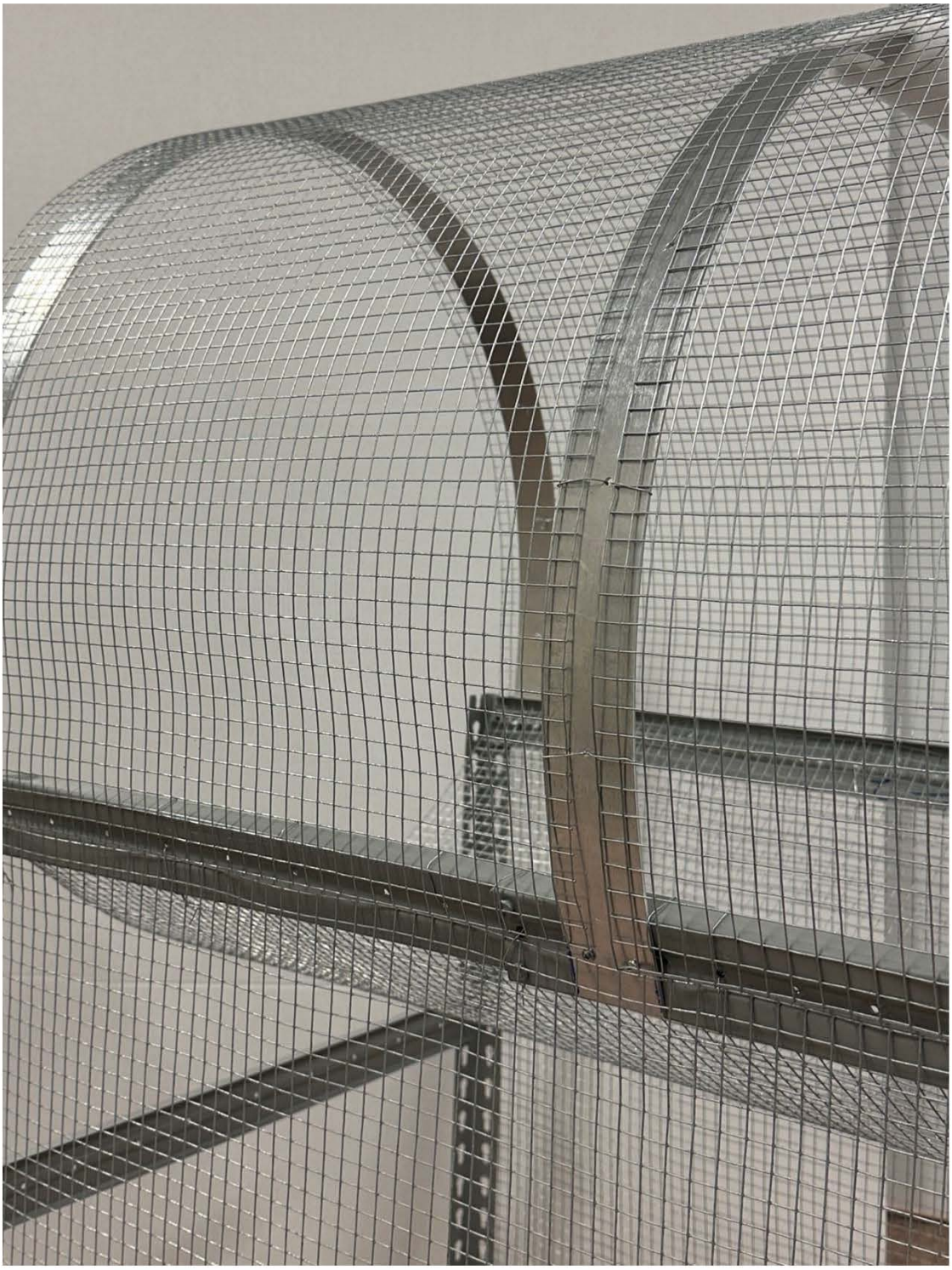


Figure 16: The process of building the model – Number 2

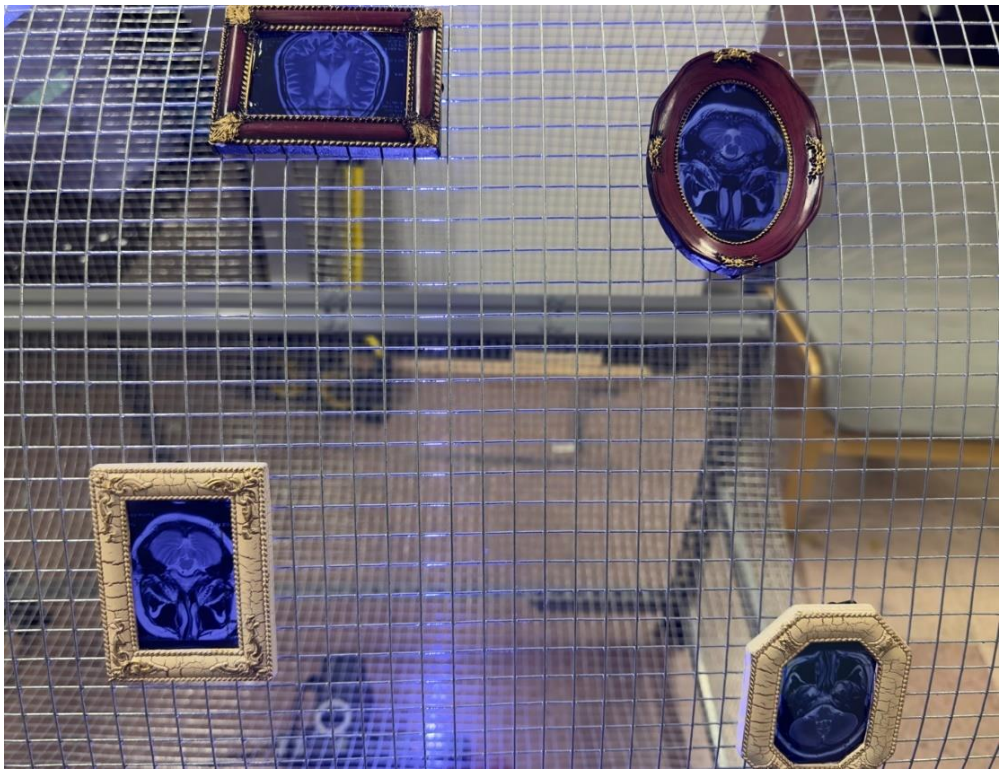


Figure 17: The process of building the model – Number 3

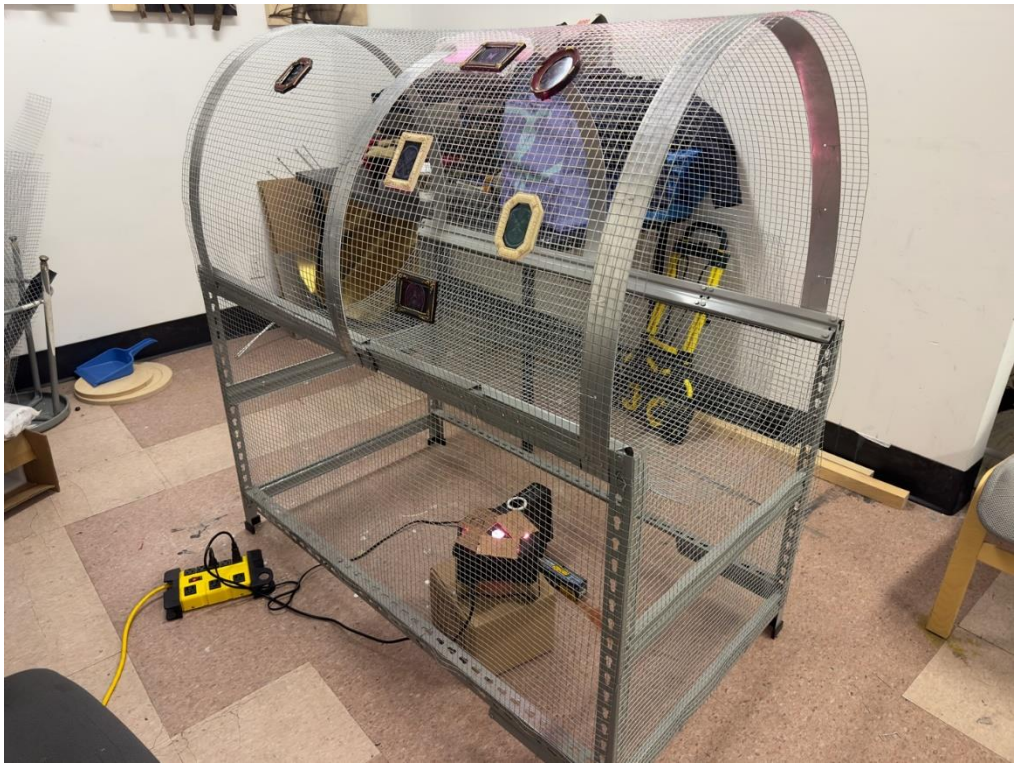


Figure 18: The process of building the model – Number 4

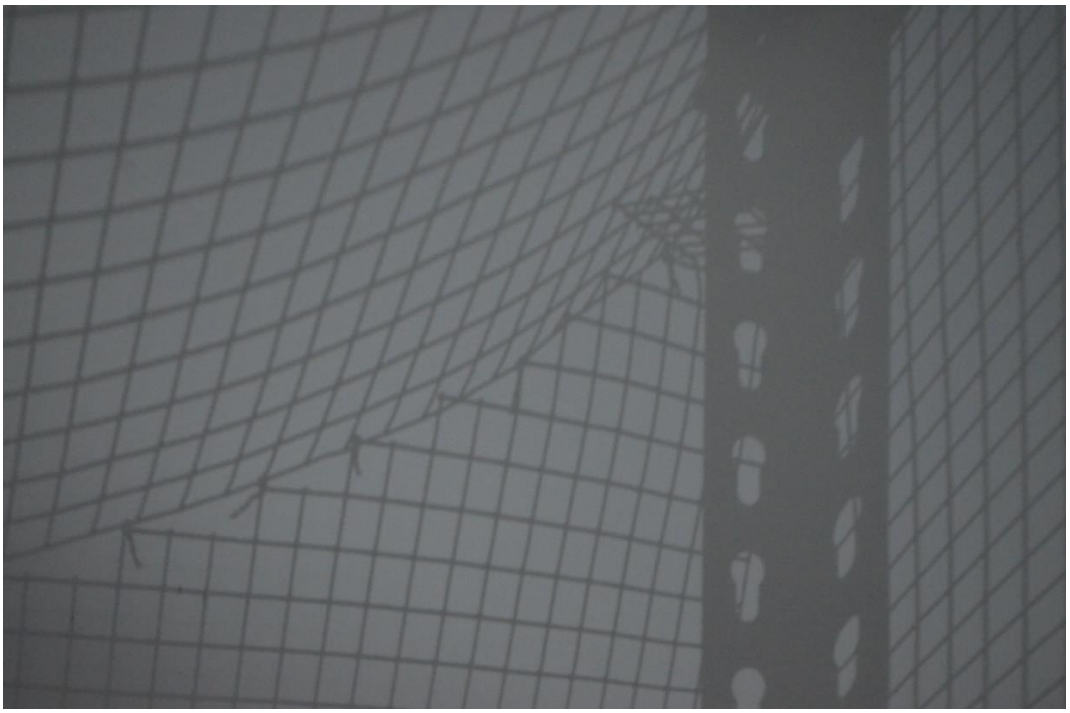


Figure 19: The process of building the model – Number 5

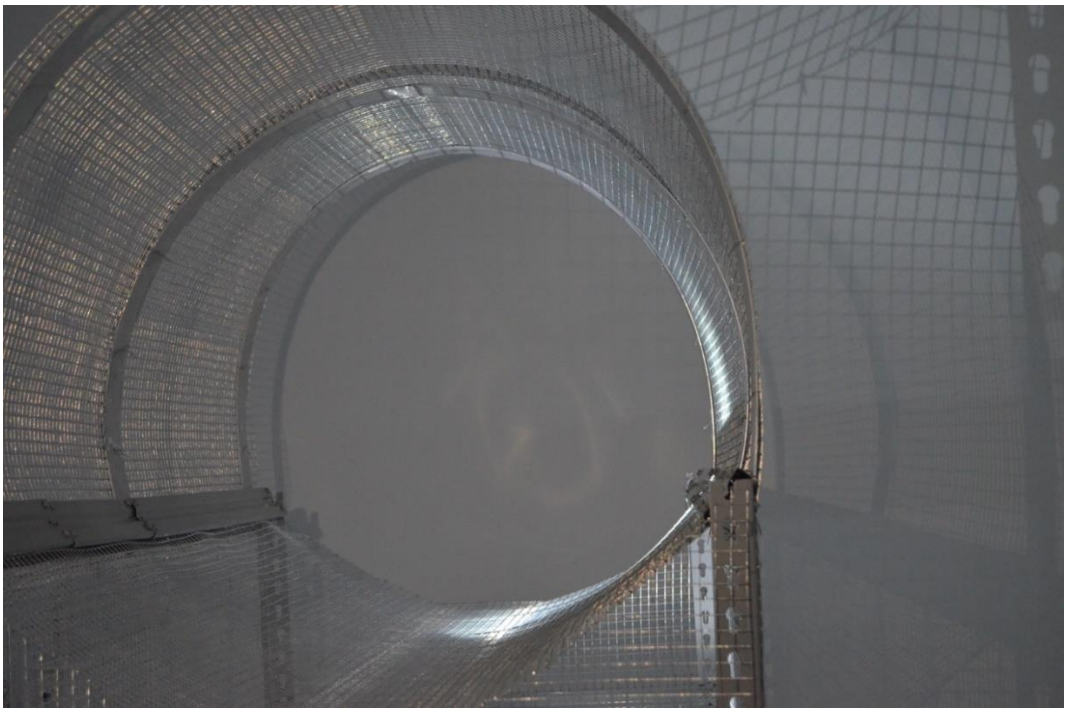


Figure 20: The process of building the model – Number 6

Figure 21: The process of building the model – Number 7

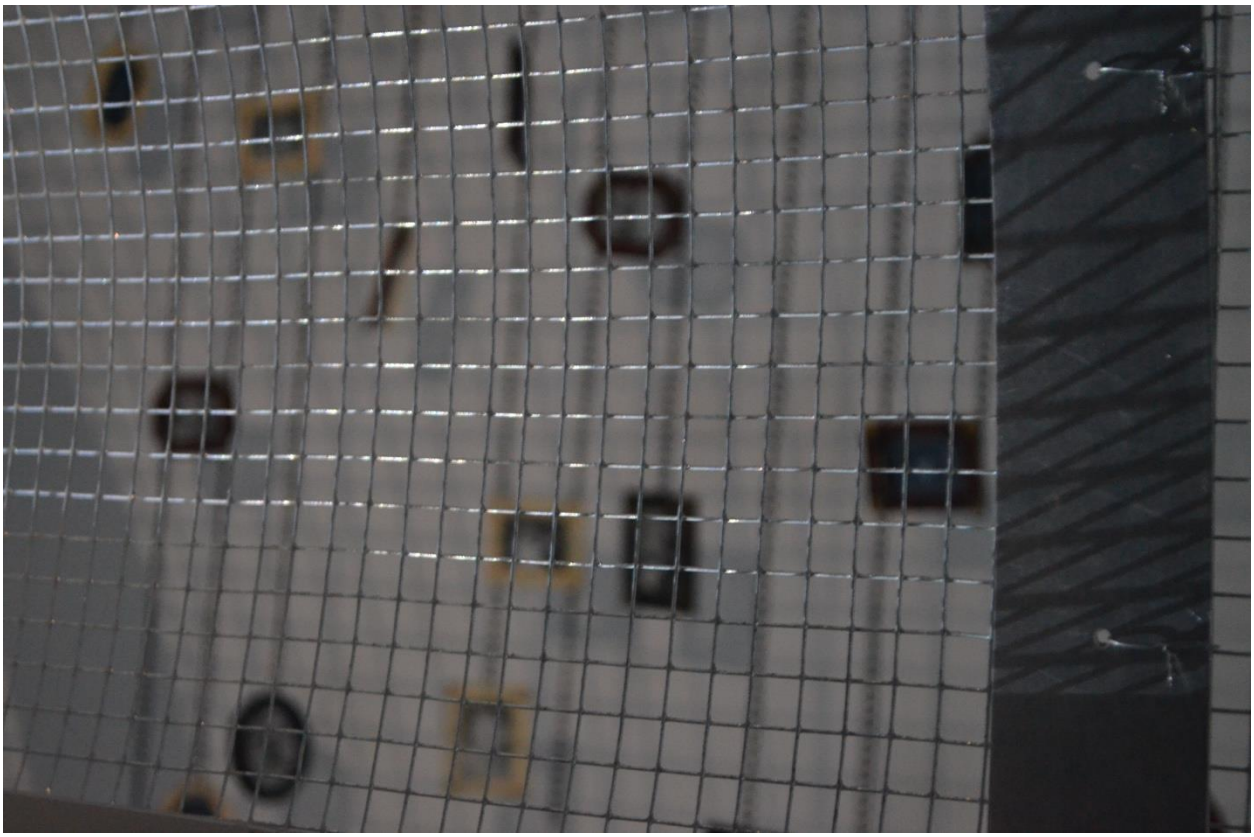


Figure 22: The process of building the model – Number 8

Figure 23: The process of building the model – Number 9

For the target state model, I have decided to compile the images of my MRI scans taken during my visits to undergo MRI procedures. These images will be showcased in an installation with controlled lighting and sound within an MRI-like environment. This approach aims to provide a unique and immersive experience that allows viewers to engage with the visual and auditory aspects of MRI scans, fostering a deeper understanding of the medical imaging process and its significance. The methodology involves carefully curating the MRI images, designing a space to replicate an MRI environment, setting up appropriate lighting and sound effects to enhance the experience, and inviting viewers to interact with the exhibit to gain insights into the world of medical imaging. Figure 15 and Figure 23 show evolving of the larger scale model from early steps to near the completion step.

My approach involves presenting a firsthand account of my journey through the extended periods during which I must undergo annual MRI scans. In the midst of distressing and unbearable sounds within the MRI scan environment, I try to evoke the hopeful voices of my loved ones and help myself in enduring the passage of time. By focusing on these uplifting memories, I aim to create a mental sanctuary that counters the challenging auditory experience. This process involves redirecting my attention towards positive feelings, allowing me to navigate the difficult moments during the scan. By summoning these comforting sounds in my mind during an MRI scan, I not only find solace but also build a resilient mindset. In my opinion, this approach transforms the MRI ordeal into an opportunity for emotional connection and personal growth.

Furthermore, in this project I am visually presenting my strategies for confronting my fears during an MRI scan, along with depicting the shadows of those fears which have a negative impact on both my body and my brain. Finally, as part of the installation (in addition to an abstract version of the MRI device), I hanged gown pieces from the ceiling, such that each piece is covered with stamp of various MRI visit dates and the word appointment. By highlighting these marks, I showcase the dedication of patients and accentuate the necessity for improved healthcare assistance to alleviate the extra challenges linked with MRI scans during non-conventional hours.

Therefore, in this section, I first focus on wait times for MRI scans in Canadian provinces, followed by the development and implementation of an installation focused on addressing the issue of claustrophobia in MRI scans. The installation is located around hanged MRI results (in form of images or shattered CDs) of fifty patients. This installation aims to raise awareness on claustrophobic feelings experienced by some patients during MRI procedures and highlight the availability of open MRI machines as an alternative solution.

Finally, I share my own personal experiences. My goal is to convey the immense pressure and stress involved in this process, which often goes unnoticed by others, including those dearest and closest to the patient. Through this research, I attempt to show the emotional state of going through an MRI from abstract to representational form and to highlight how this experience can negatively impact a patient's overall well-being.

Autoethnography Research Approach

I was diagnosed with multiple sclerosis (MS) 18 years ago. Each person's experience with MS is individual and unique, and managing the disease is also different for each person depending on the stage of MS, lifestyle, and prior health conditions. So far, no ultimate cure has been found for MS (Gohil 605). Current treatments focus on slowing down the progress of the disease. Weekly injection of Avonex is a common treatment of MS to slow down the progress of disability and reduce the number of MS attacks. Although weekly injection of Avonex helps to control the progress of the MS, it has its own side effects including headache, fatigue, numbness of hands/feet, fever, and muscle ache[29].

For me, undergoing an MRI scan at least once a year has become an essential part of my life. This routine scan is essential and needs to be done each year prior to visiting the neurologist. In other words, MRI scans have become a vital component of my ongoing journey with MS, helping to monitor its progress and evaluate any potential changes.

I have been struggling with the fear of progression of my disease and attending MRI scans at least once a year since the beginning of this journey. Although the Canadian healthcare

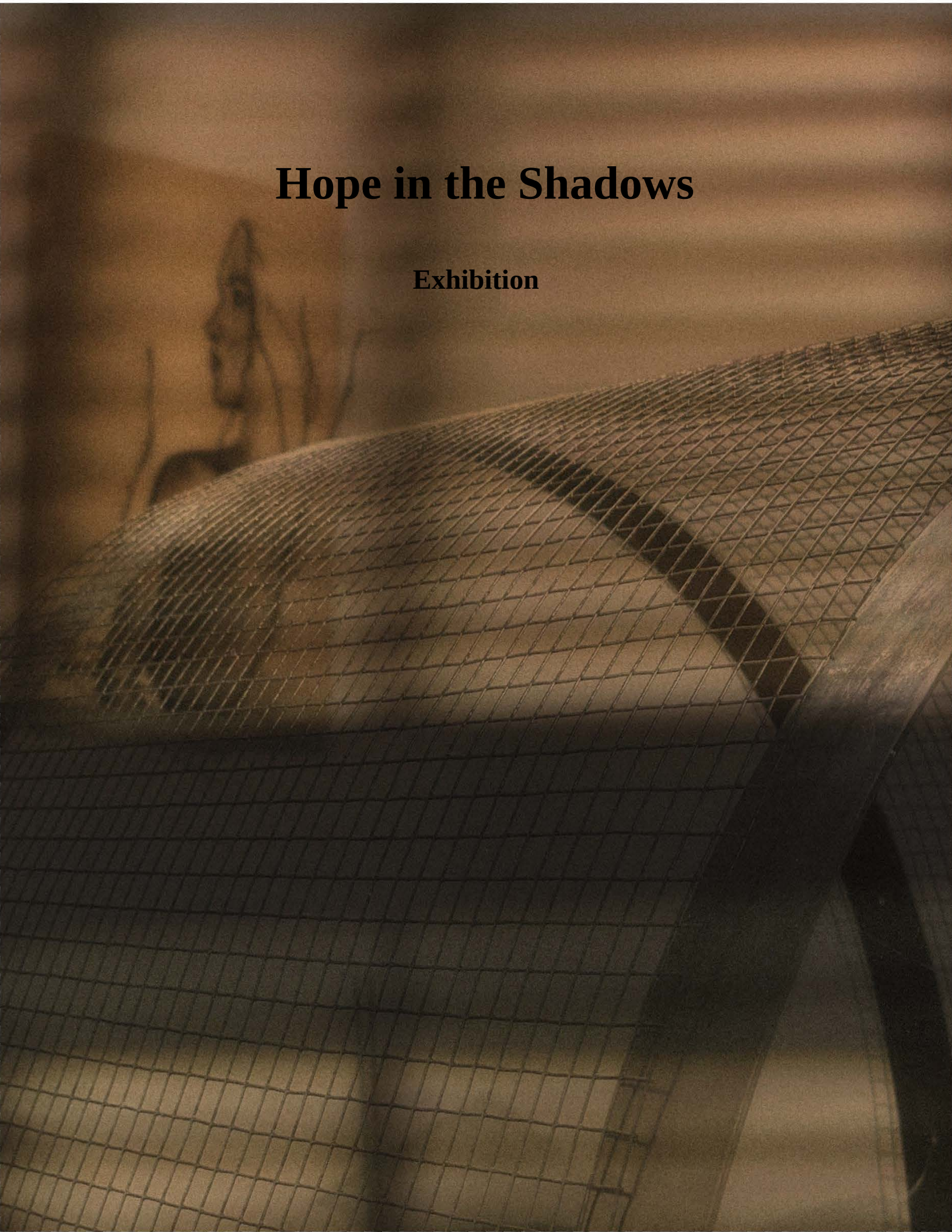
[29] https://www.avonex.com/en_us/home/why-avonex/safety-and-side-effects.html

system is known for its universal accessibility and high quality of care, it has its own weaknesses as well. Based on my personal experience, one of such weaknesses is the extended wait times for MRI appointments. While high quality of healthcare system in Canada is undeniable, these long waiting times have become a challenge for people with MS. Uncertainty about my next appointment time, combined with the knowledge that my condition may worsen during these delays, has heightened the level of anxiety and nervousness I personally experience.

According to University Health Network (UHN), MRI appointments are scheduled 24 hours a day, 7 days a week[30]. Therefore, a patient may have an appointment after normal business hours or on the weekend. As a result, if a patient is more than 15 minutes late, she may need to reschedule her appointment as the hospital has MRI appointment 24 hours a day. Based on my personal experience, in addition to delays, it seems that late night appointments have become more common in Toronto. My last five appointments for MRI scans were all between 1 am to 5 am. These nighttime appointments, which are impossible to reschedule without facing significant delays, introduce additional discomfort and stress into the overall process. During my late-night visits, I have observed older patients with MS facing even greater difficulties with these appointments. Their age, challenges associated with MS, stress of going through MRI scan, and having to wait hours late at night in hospital make the entire process seem like a nightmare for them. The elderly population are susceptible to fatigue and disorientation during late hours, which increases the risk of falls or accidents while navigating healthcare facilities. Furthermore, Individuals may find it difficult to transport to and from medical facility during afterhours. The absence of public transit services during late-night hours may lead to missing appointment, which can delay diagnosis and treatment.

[30] https://www.uhn.ca/MedicalImaging/Labs_Tests/MRI

The pressure and stress involved in this process often goes unnoticed by others, including those closest to the patient and especially by policy makers. I hope that sharing my personal experience of undergoing the annual MRI process can provide insights into the emotional challenges that patients face. This may help to draw attention to the potential negative impacts on an individuals' well-being and contribute to enhancing healthcare outcomes for all Canadians.



Hope in the Shadows

Exhibition

Reflections

Hope in the Shadows is an artistic exploration into the hidden realms of pain and suffering that pervade human existence, often concealed beneath the surface of everyday life. Through a journey spanning eighteen years within the convoluted corridors of the healthcare system, this exhibition delves into personal struggles and critically examines patient care, with a particular focus on the experiences of individuals battling Multiple Sclerosis (MS).

The installation captures the silent suffering endured by countless individuals, from the claustrophobic fears elicited by the confined spaces of MRI machines to the interminable waits for critical tests that are often delayed. This exhibition seeks to transform the intangible agony associated with medical imaging into a tangible and vivid expression, advocating for a healthcare system characterized by efficiency and compassion.

Exploring healthcare systems from personal, social, and political perspectives, the exhibition calls for the recognition and correction of systemic issues. It combines personal stories with critical analysis of the current healthcare system to increase awareness of the complex challenges that patients face.

A key theme of this artistic journey is the motif of cages, both literal and figurative, symbolizing the existential constraints individuals face within the healthcare maze. The exhibition uses evocative imagery and narratives to encourage visitors to reflect on the profound isolation and limitations experienced by patients. It aims to foster a deeper understanding of the need for empathy, unity, and systemic change. *Hope in the Shadows* invites viewers to see patient care through a new lens, advocating for a collective effort towards a more compassionate and equitable healthcare system.

This exhibition comprised of four main parts:

1. MRI Installation,
2. MRI Images and Photos around the MRI Installation,
3. Shattered CDs and Cut MRI Images,
4. Hospital Gown.

The rest of this section is devoted to documenting each part of the exhibition.

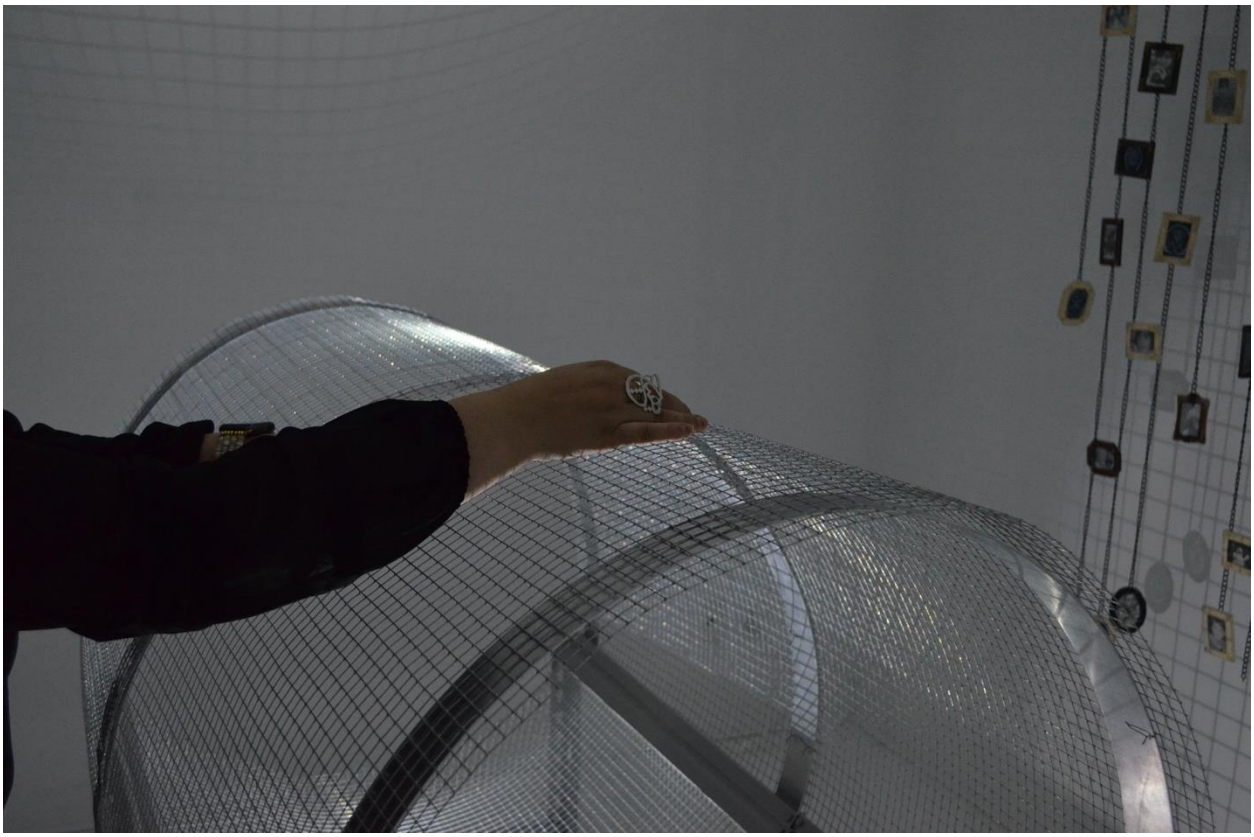


Figure 24: Hope in the Shadows (Exhibition)

MRI Installation

The envisioned installation, a life-sized MRI cage adorned with rotating white lights and diverse sounds, powerfully captures how external stimuli interact with the subconscious mind, evoking

and reshaping memories. This setup combines the restrictive feel of an MRI with a soundscape that bridges personal memories and broader tragedies, creating a strong metaphor for how we process mental and emotional experiences.

Inside the MRI installation, blue laser lights project animated patterns on the ceiling, representing the magnetic fields that encircle the human body during a scan. These animations transform the auditory experience into visual forms, adding another layer of sensory engagement.

The intimidating noise of the MRI machine, inherently anxiety-inducing, is softened by comforting sounds like piano melodies from my son and the reassuring voices of my parents. These sounds provide solace and emotional grounding, pulling deep-seated memories to the forefront of the subconscious. The installation features classical pieces like “Love Theme from Romeo and Juliet” and “Fur Elise”, which add depth and can evoke different reactions based on personal connections to the music. Played in this unique setting, the music acts as a bridge between universal feelings and personal experiences, touching shared human emotions while exploring individual emotional landscapes. This juxtaposition is further deepened by the integration of distressing sounds, such as those from the Ukrainian plane crash, adding complex emotional layers to the soundscape.

The MRI’s cage-like structure, paired with this rich blend of sounds, symbolizes both the confinement of the mind under stress and its ability to transcend physical boundaries through memory and sound. This reflects how both music and voices—remembered or heard—can transport individuals to comforting or painful moments, shaping our internal worlds.

Furthermore, the shifting shadows cast by the MRI device, highlighted by rotating lights, introduce a visual dimension to the installation. These shadows mimic the fleeting and changing

nature of thoughts and memories as they move across the space, underscoring the fluid and transient nature of human memory and perception.

Overall, this installation tries to demonstrate the significant impact of sound on our psyche, showing how it can unearth memories from our subconscious and significantly affect our emotional state, particularly in challenging environments. By including classical music and familial voices, the installation enriches this narrative, offering a language that connects individual experiences to a wider array of human emotions and stories. Find below few photos from this section of the exhibition.

Figure 25: MRI Installation - Number 1

Figure 26: MRI Installation - Number 2

Figure 27: MRI Installation - Number 3

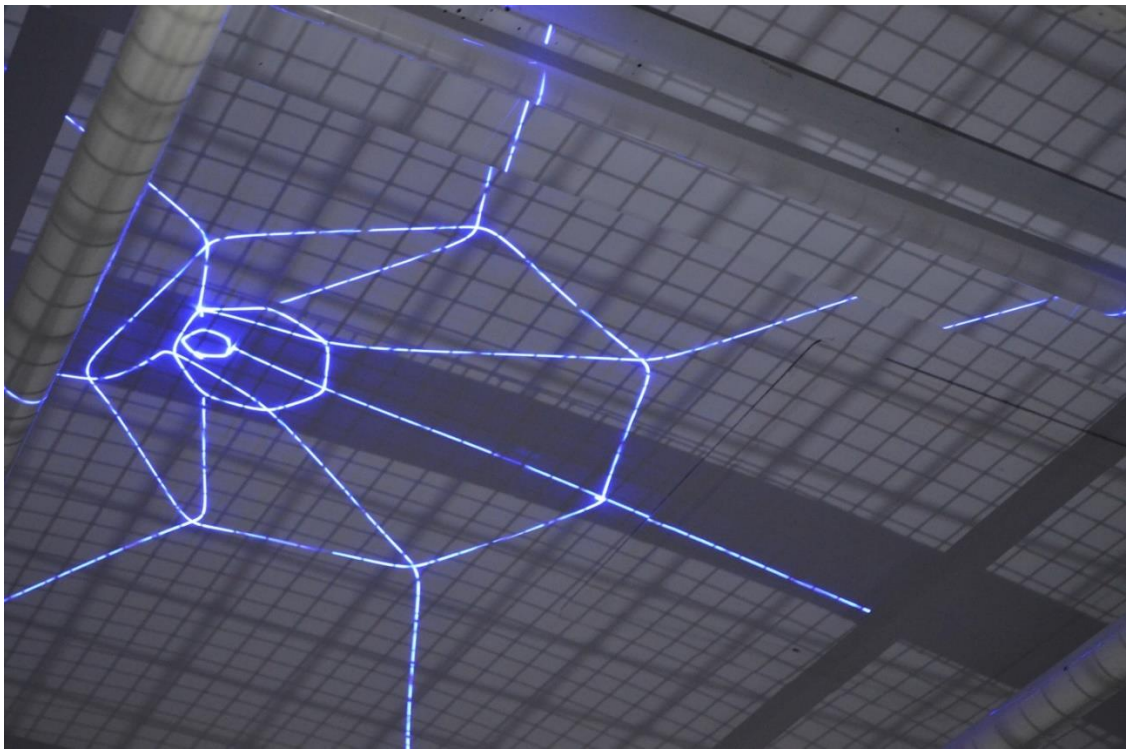


Figure 28: MRI Installation - Number 4

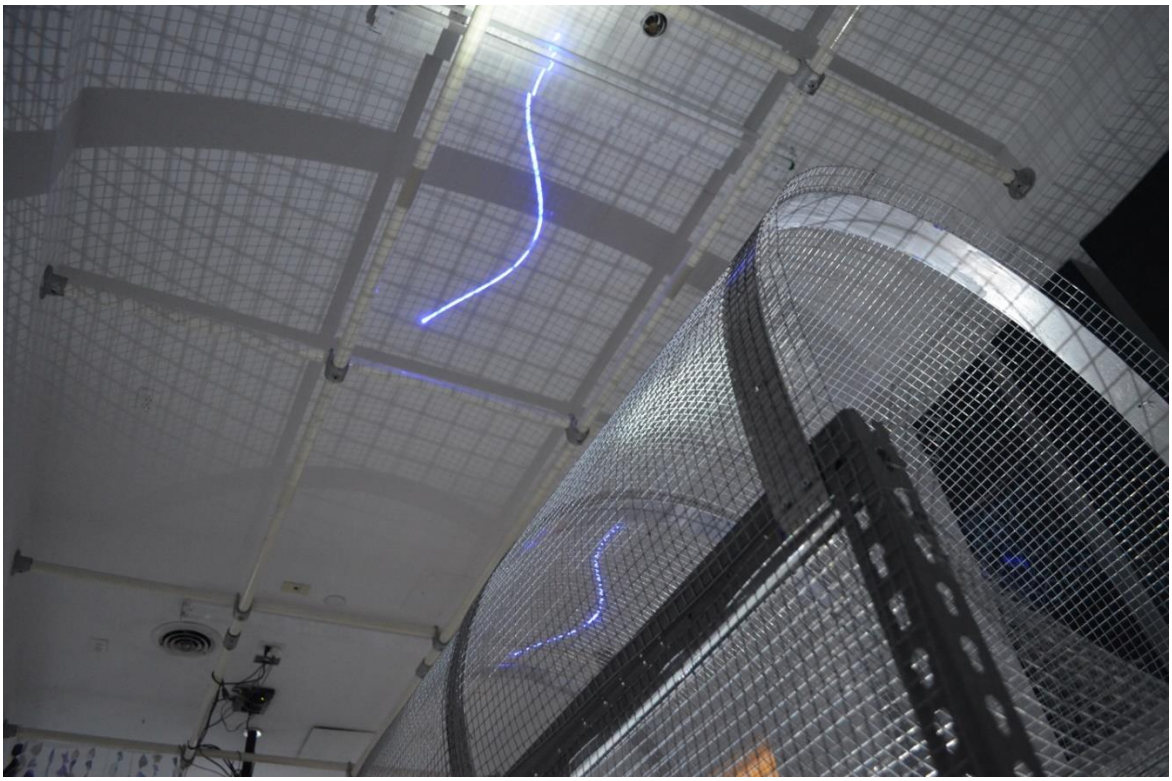


Figure 29: MRI Installation - Number 5

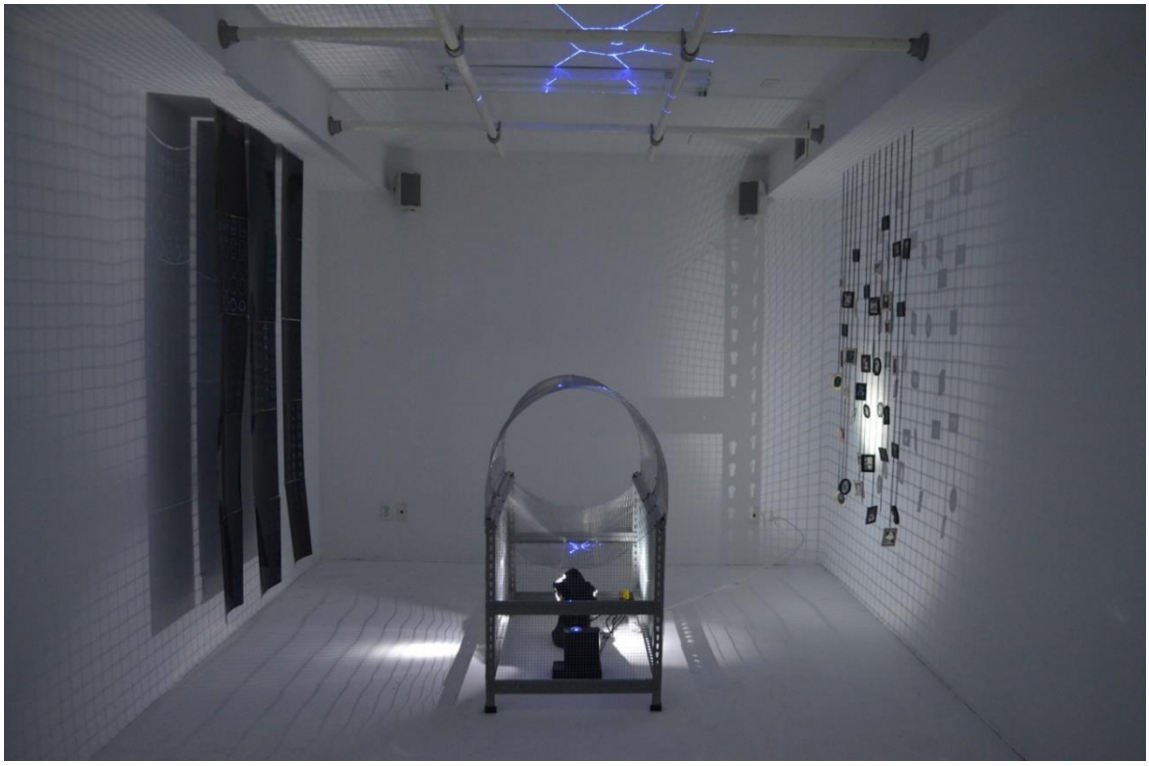


Figure 30: MRI Installation - Number 7

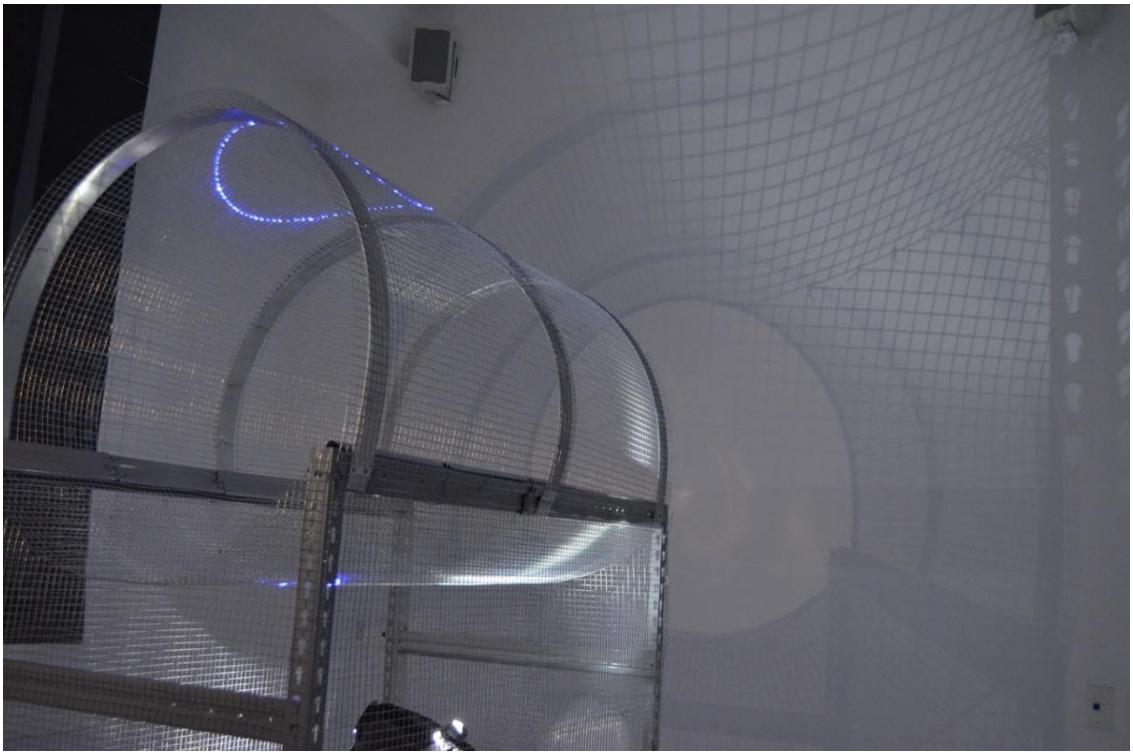


Figure 31: MRI Installation - Number 8

Figure 32: MRI Installation - Number 9

MRI Images and Photos around the MRI installation

This installation juxtaposes personal photographs with MRI images (obtained from over fifty individuals), creating a narrative that explores the intersection of illness, memory, and the enduring impact of medical interventions. On one side of the installation are original photographs and initial medical images that diagnosed the condition. On the other, there are photographs capturing memories recalled during eighteen years of MRI experiences, where certain moments have been permanently imprinted onto these images.

Central to the display is a life-sized MRI setup, around which these photographs are arranged. This setup not only serves as a visual anchor but also projects shifting shadows over the photographs, symbolizing the profound and far-reaching effects of the MRI experience on patients. These shadows, moving gently across all photographs and surfaces, vary in intensity—sometimes appearing bright and hopeful, other times dark and cold, mirroring the emotional spectrum that patients with incurable diseases often experience.

Additionally, the installation includes side-by-side images of two brains, one from a person with MS and the other from a healthy brain MRI. This installation tries to illustrate the unseen struggles of people with chronic illness, particularly highlighting how those closest to us may not fully grasp the depth of our pain.

This narrative installation poignantly captures how medical imaging like MRI intersects deeply with personal narratives and memories, revealing not only physical afflictions but also the emotional and psychological tolls of living with a chronic illness. The interplay of light and shadow over the photographs serves as a powerful metaphor for the fluctuations of hope and despair that characterize the lives of those living with such conditions. Find below few photos from this section of the exhibition.

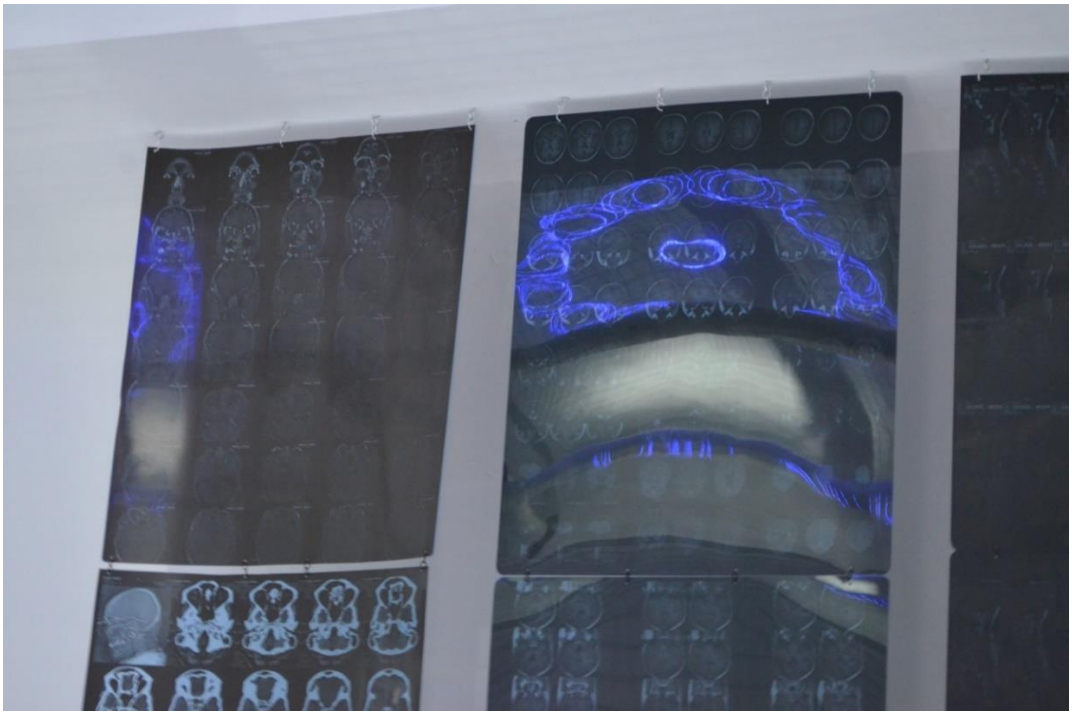


Figure 33: MRI Images - Number 1

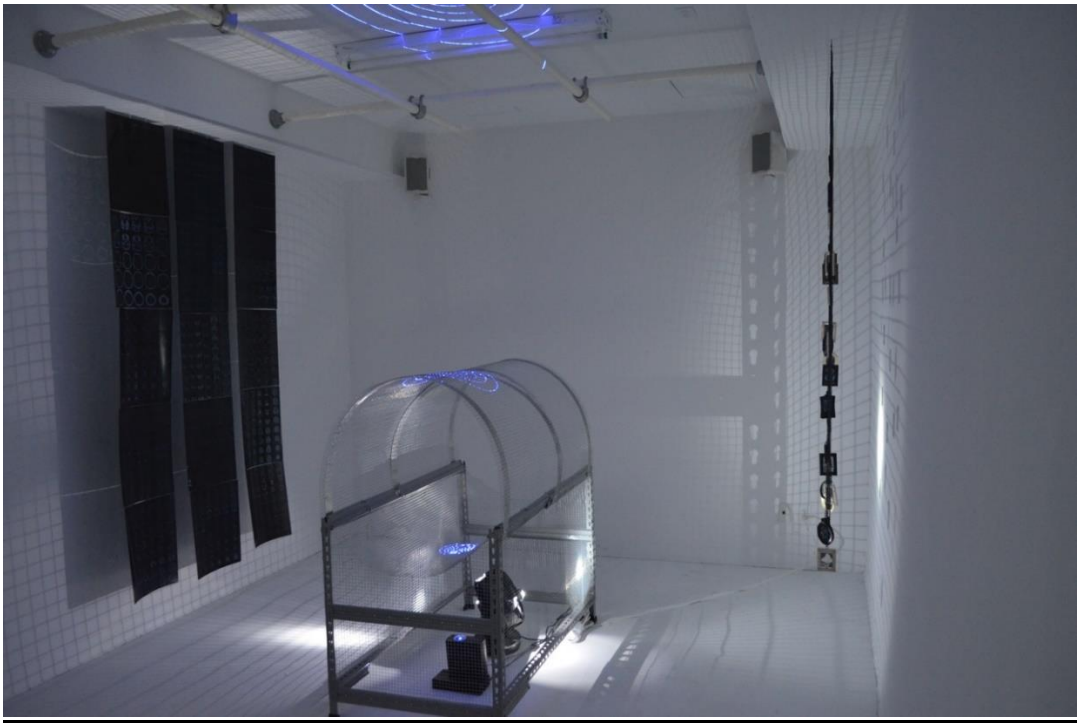


Figure 34: Overview of MRI Images

Figure 35: MRI Images - Number 2

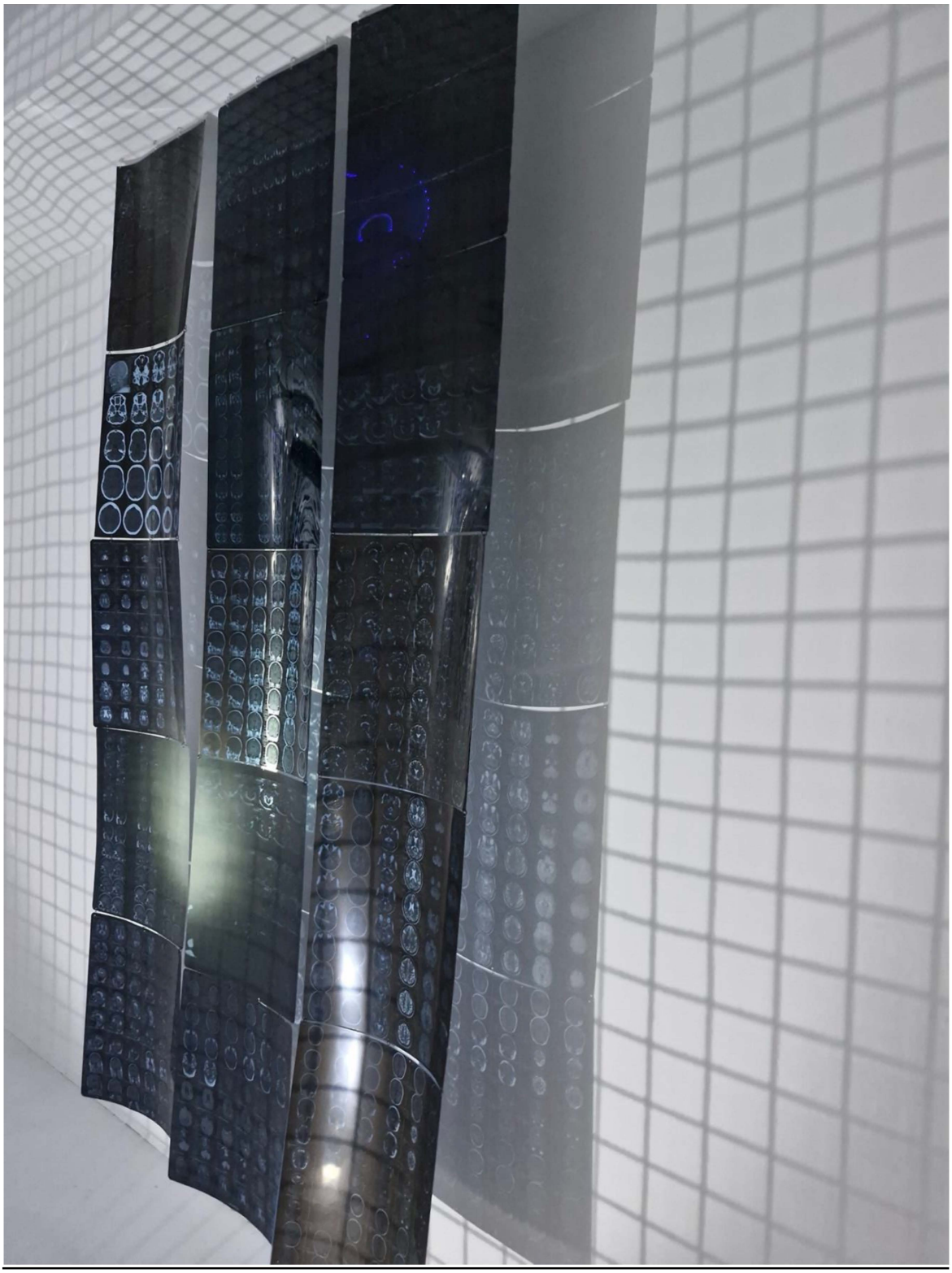


Figure 36: MRI Images - Number 3

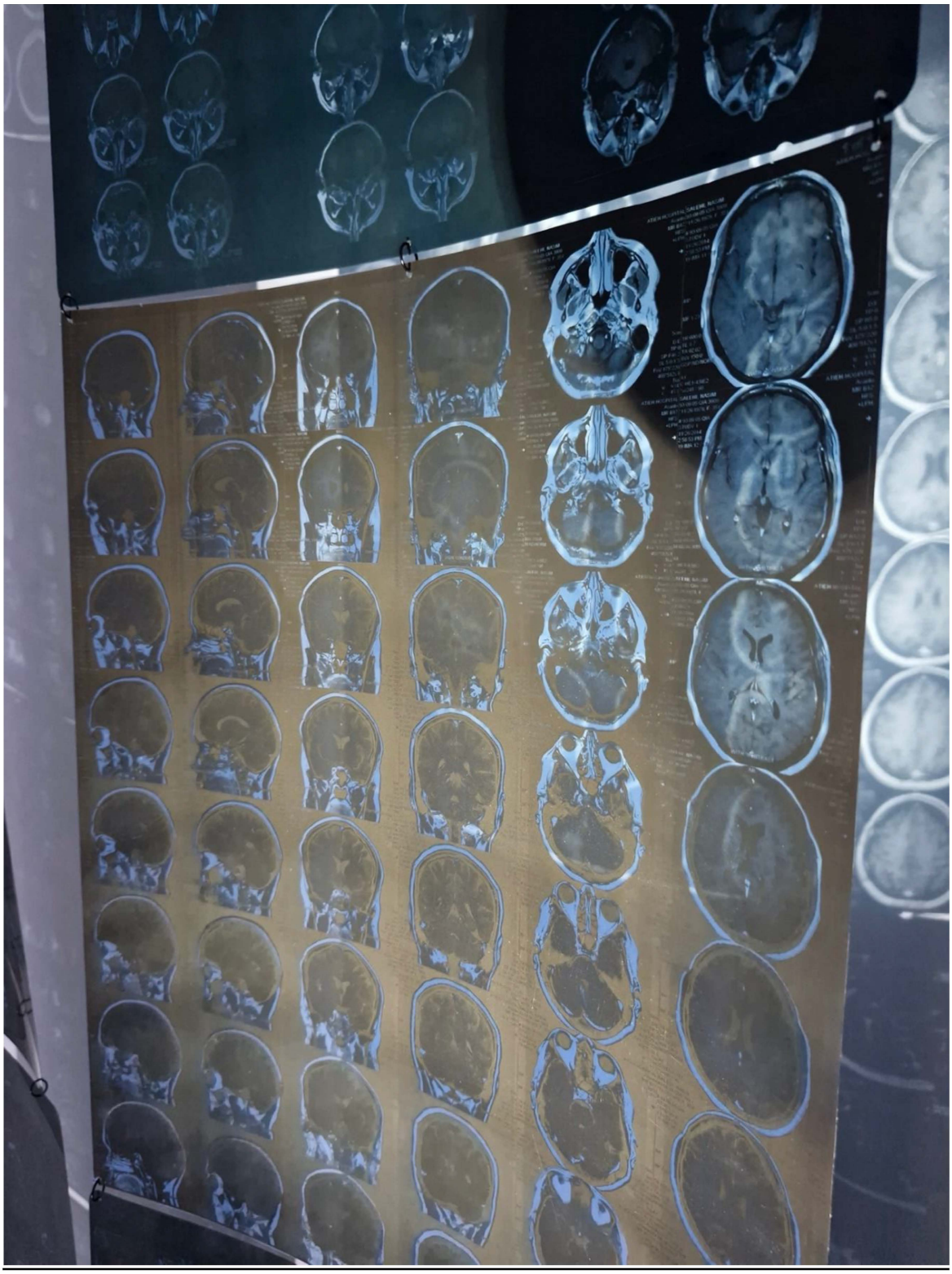


Figure 37: MRI Images - Number 4

Figure 38: MRI Images - Number 5

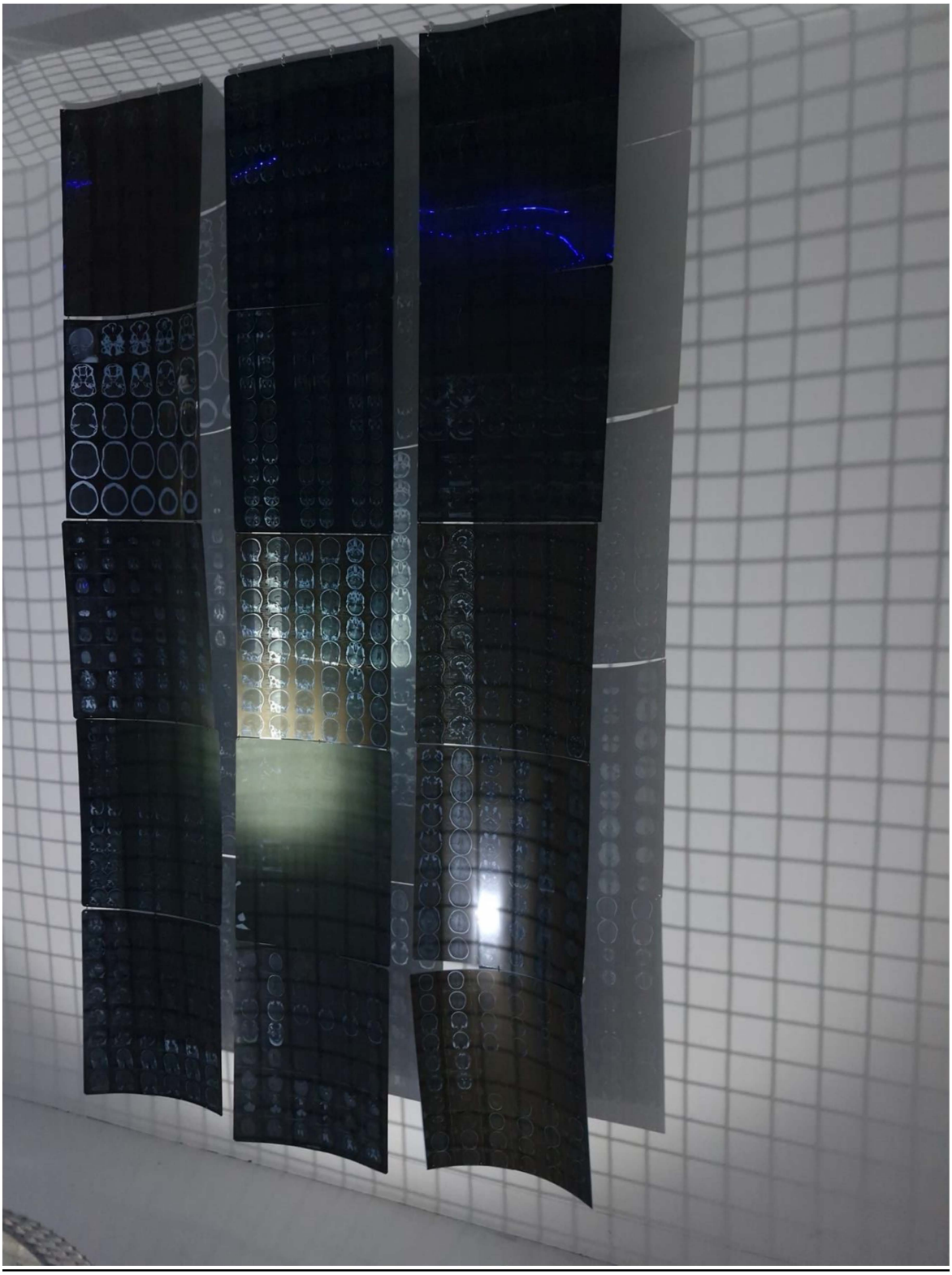


Figure 39: : MRI Images - Number 6

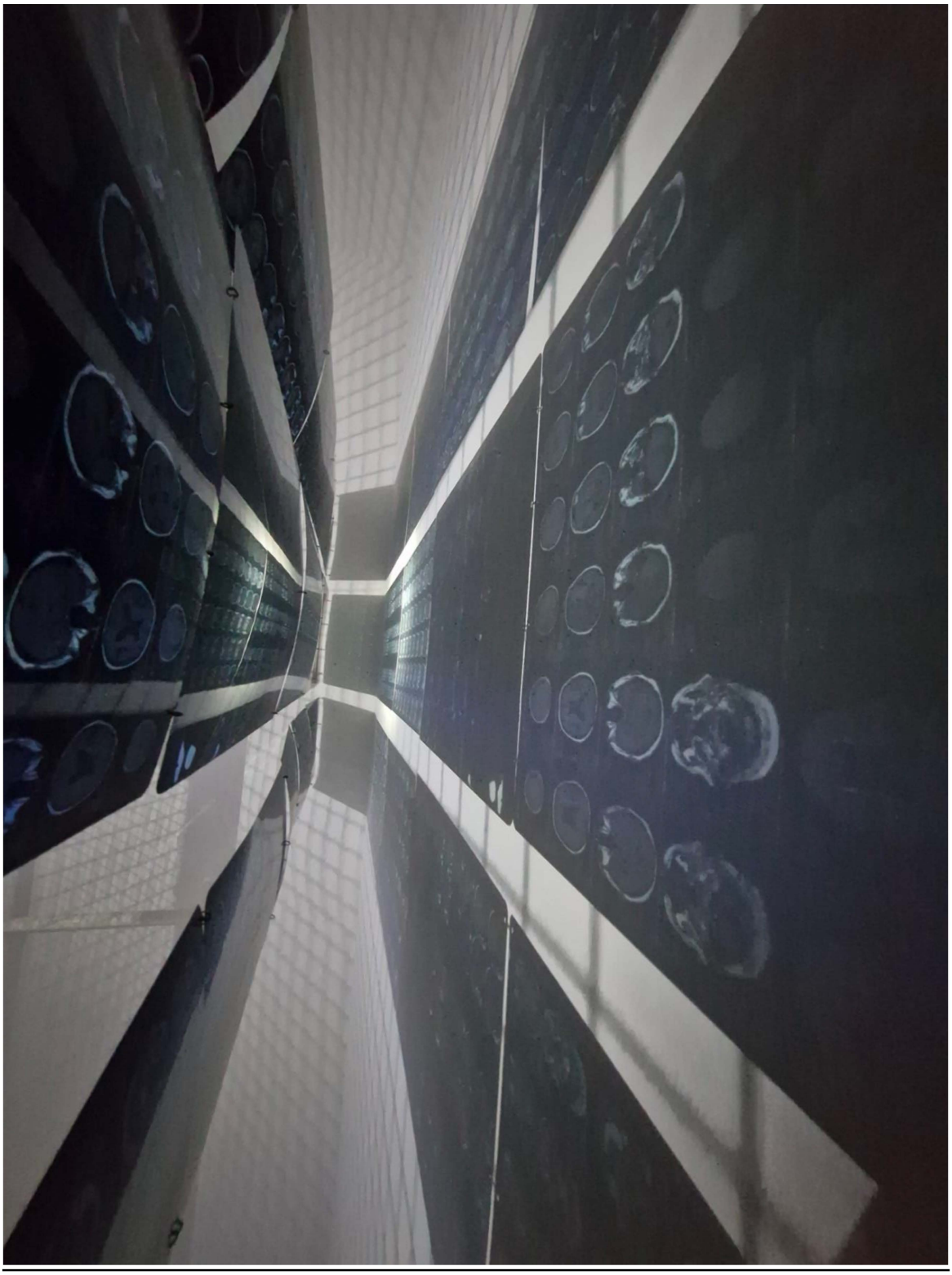


Figure 40: Shadows on the wall – Number 1

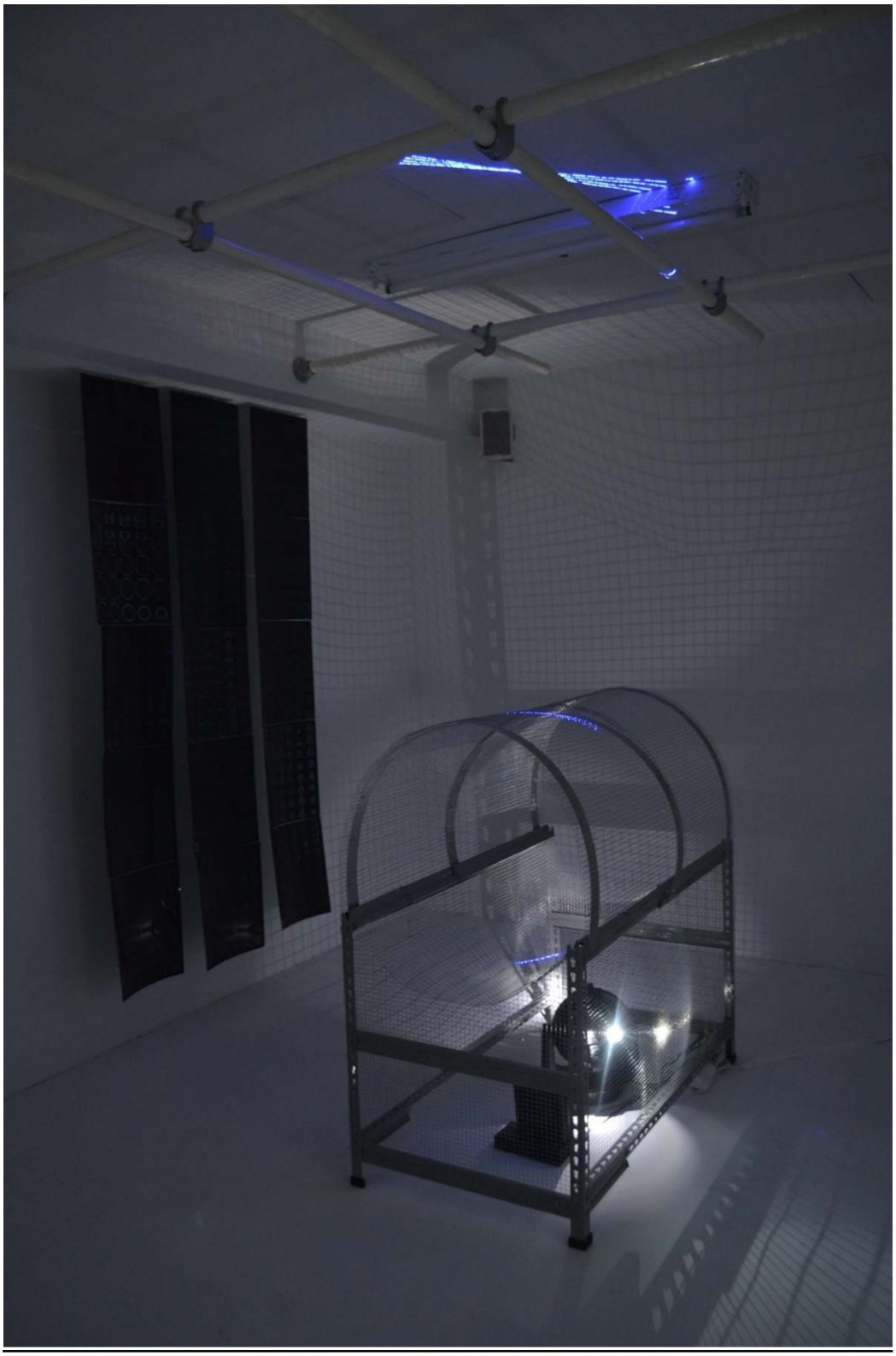


Figure 41: Shadows on the wall - Number 2

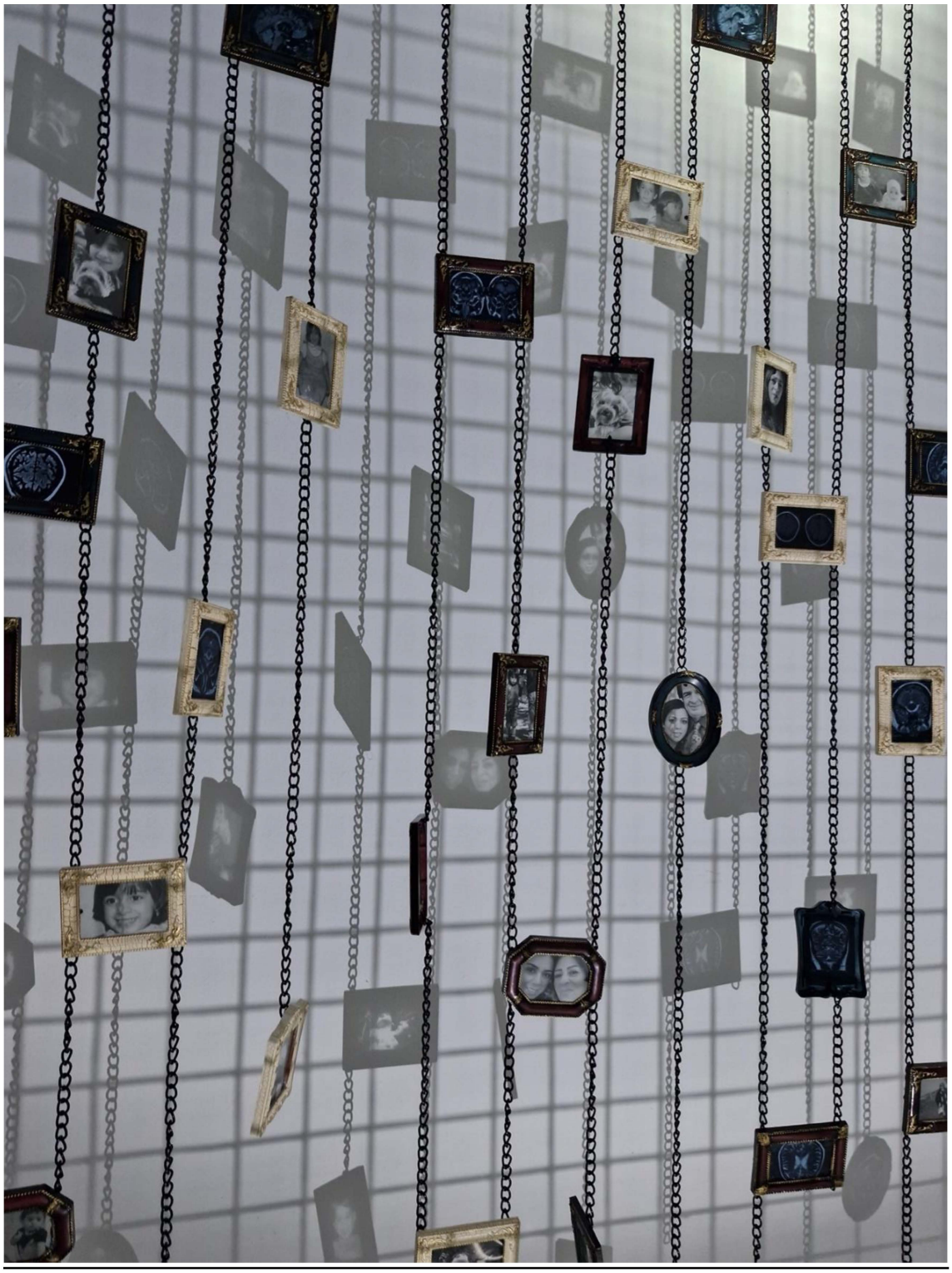


Figure 42: Hanged photos - Number 1

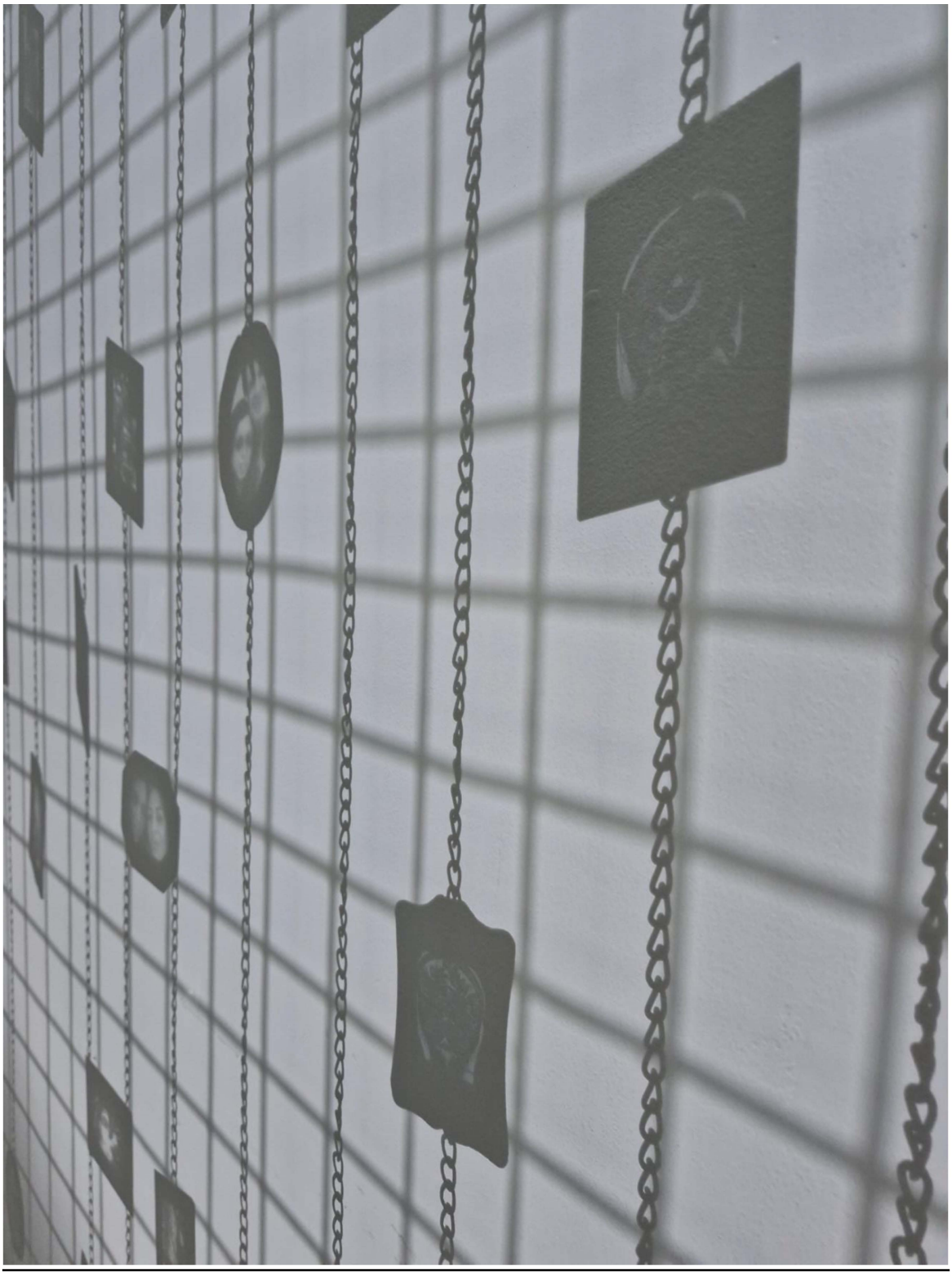


Figure 43: Shadow of hanged photos on the wall - Number 1

Figure 44: Hanged photos - Number 2

Figure 45: Shadow of hanged photos on the wall - Number 2

Figure 46: Shadows of hanged photos on the wall - Number 3

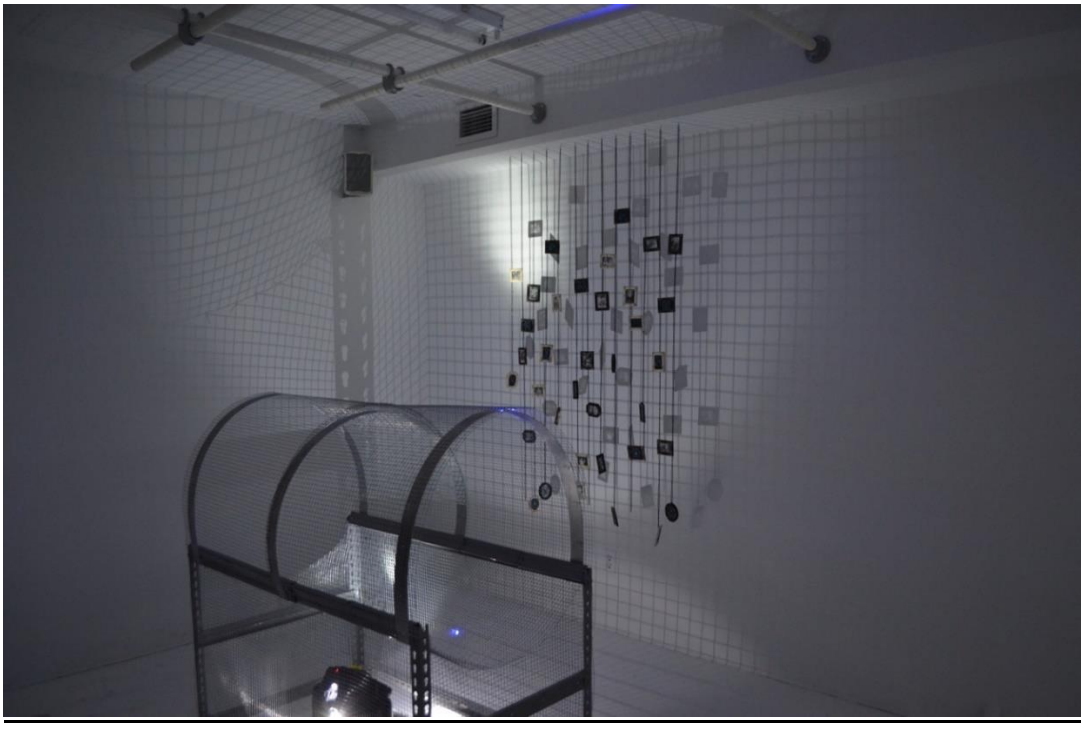


Figure 47: Shadows on the wall

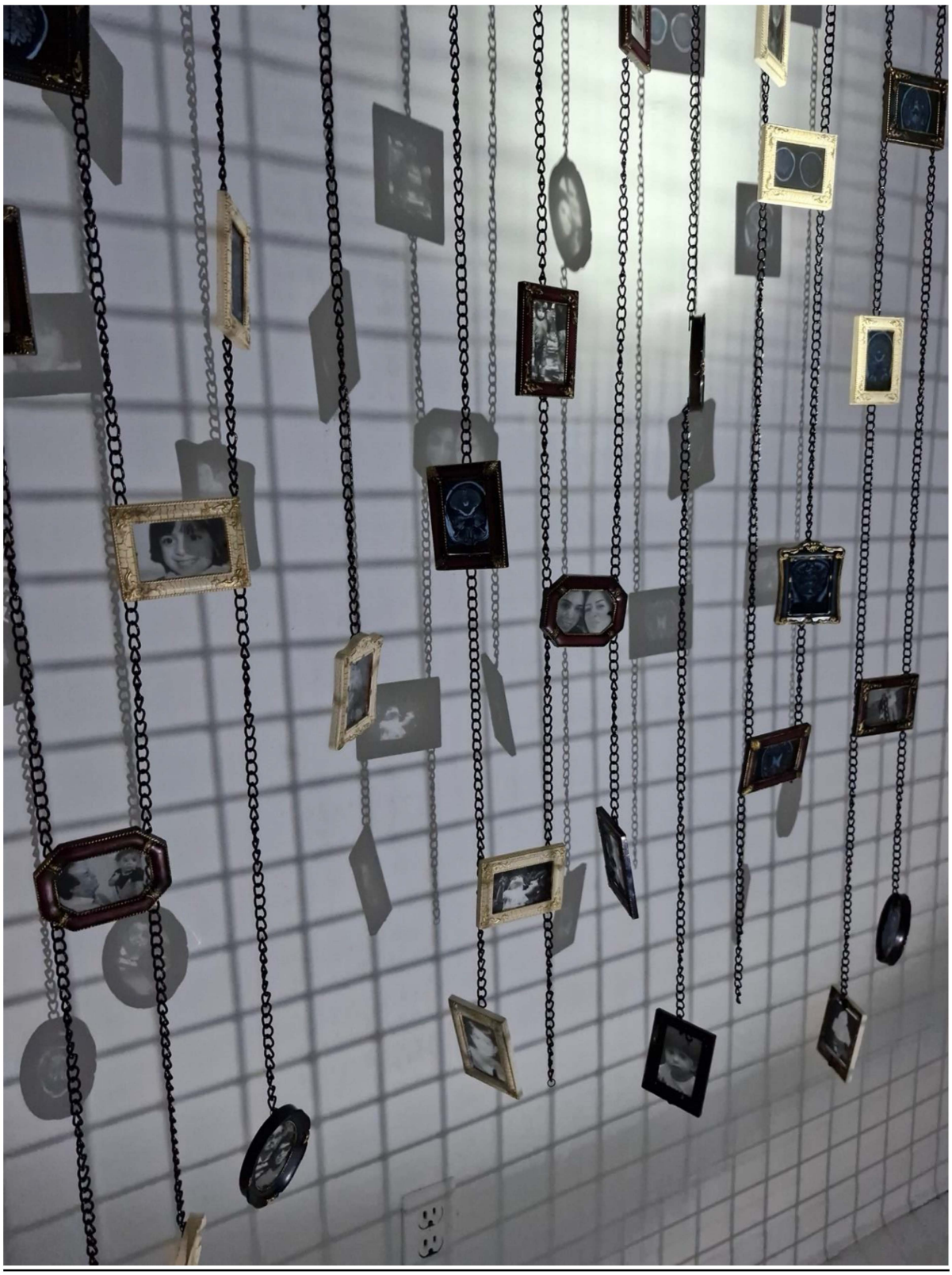


Figure 48: Shadows of hanged photos on the wall - Number 4

Figure 49: Shadows of hanged photos from a different angle - Number 1

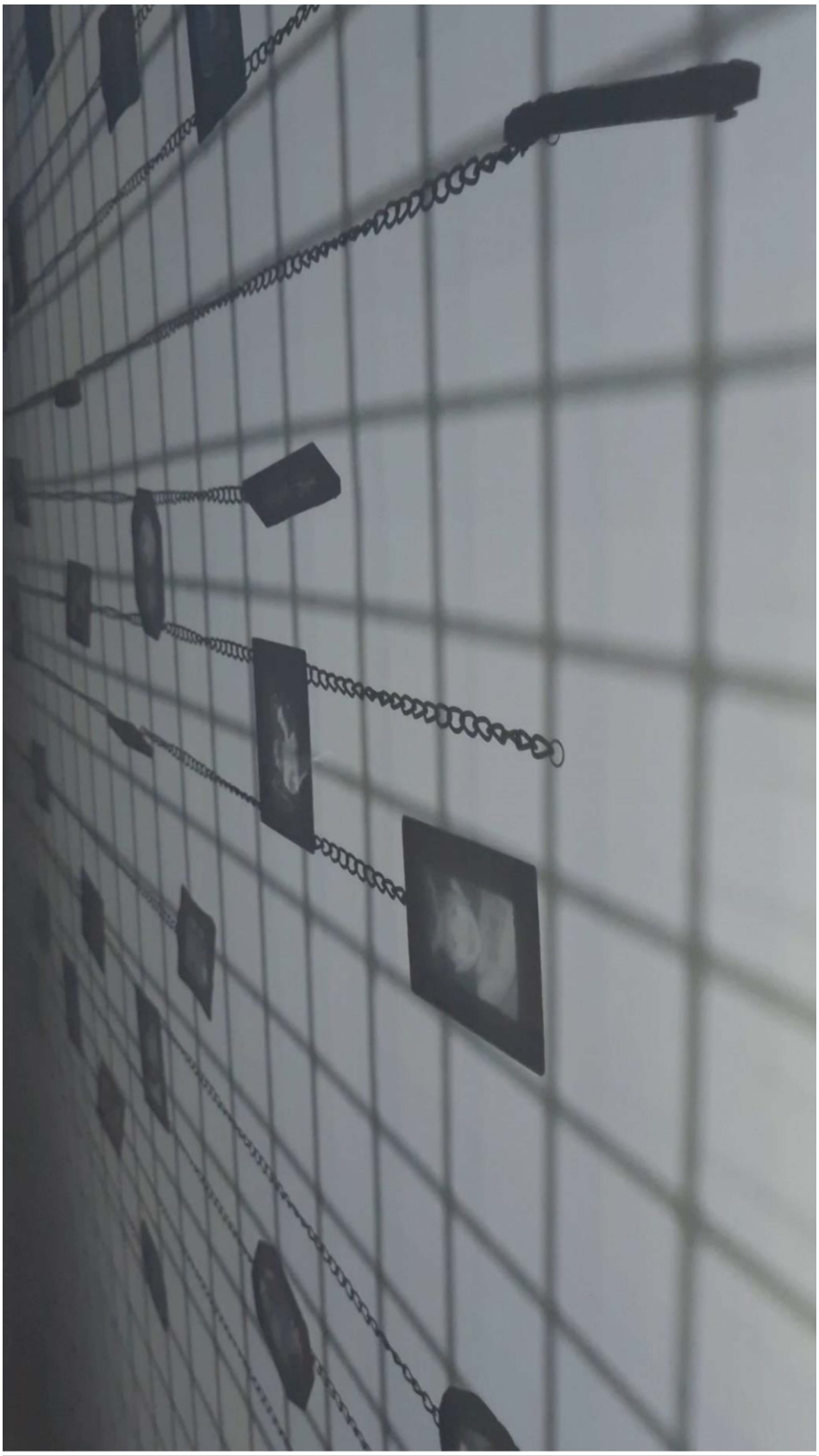


Figure 50: : Shadows of hanged photos from a different angle - Number 2

Shattered CDs and Cut Images

This part of installation reflects the experiences of people who have undergone multiple MRI scans in their lives, obtained from over fifty different patients. It reflects the often-unseen challenges that patients endure throughout MRI processes, shedding light on their anxiety, inconvenience, and systemic inefficiencies. Broken CDs and meticulously cut photographs are suspended from the ceiling, casting shadows that symbolize the deep and persistent fears and uncertainties these patients face.

These shadows represent not only past fears, but also ongoing anxieties specifically related to the Canadian healthcare system, such as long waiting times and poorly timed appointments, in addition to the claustrophobia from the MRI scans themselves. My goal with this installation is to showcase a community of individuals who are dealing with the various issues surrounding the MRI process, such as:

1. Long waiting lists that can delay diagnosis and treatment,
2. Appointment times that are often scheduled for late at night or early in the morning, which can be inconvenient and disrupt normal daily routines,
3. Difficulty in rescheduling appointments, which, given the long waiting lists for MRIs, often results in delays of several months,
4. Nervousness before and during the scan due to claustrophobia.

The installation captures both the tangible materials used and the ghostly imprints of moving shadows and lights on the walls, evoking the claustrophobic feeling of being inside an MRI machine. Sounds add another layer to the atmosphere, enveloping the viewer and intensifying the immersive experience.

The shattered CD, originally used to store MRI records, symbolizes the fading of memory. The reassembly of these fragments into a grid pattern on the wall further illustrates the process of

reorganizing and restructuring these broken memories. This aspect of the installation speaks to themes of decay and reconstruction, emphasizing the ongoing challenge of dealing with medical experiences and their impact on personal memory.

Additionally, the setup includes an interactive feature where the movement of viewers change the position of projected rainbows. These rainbows symbolize the elusive nature of hope amid these trials. This dynamic component not only engages viewers physically but also emotionally, as it underscores the struggle to find optimism in daunting circumstances. The use of light and shadow in the installation serves a dual purpose: while the shadows depict the often-grim reality of medical procedures, the rainbow suggests a persistent, albeit challenging, possibility of positive outcomes. The installation challenges the audience to consider the personal impacts of medical system inefficiencies on individual lives. It urges viewers to acknowledge the emotional and physical toll of medical diagnostics, juxtaposed with the potential for finding resilience and hope. This work not only showcases the artist's deep empathy for those affected but also critiques the broader healthcare system's shortcomings in meeting the needs of its most vulnerable.

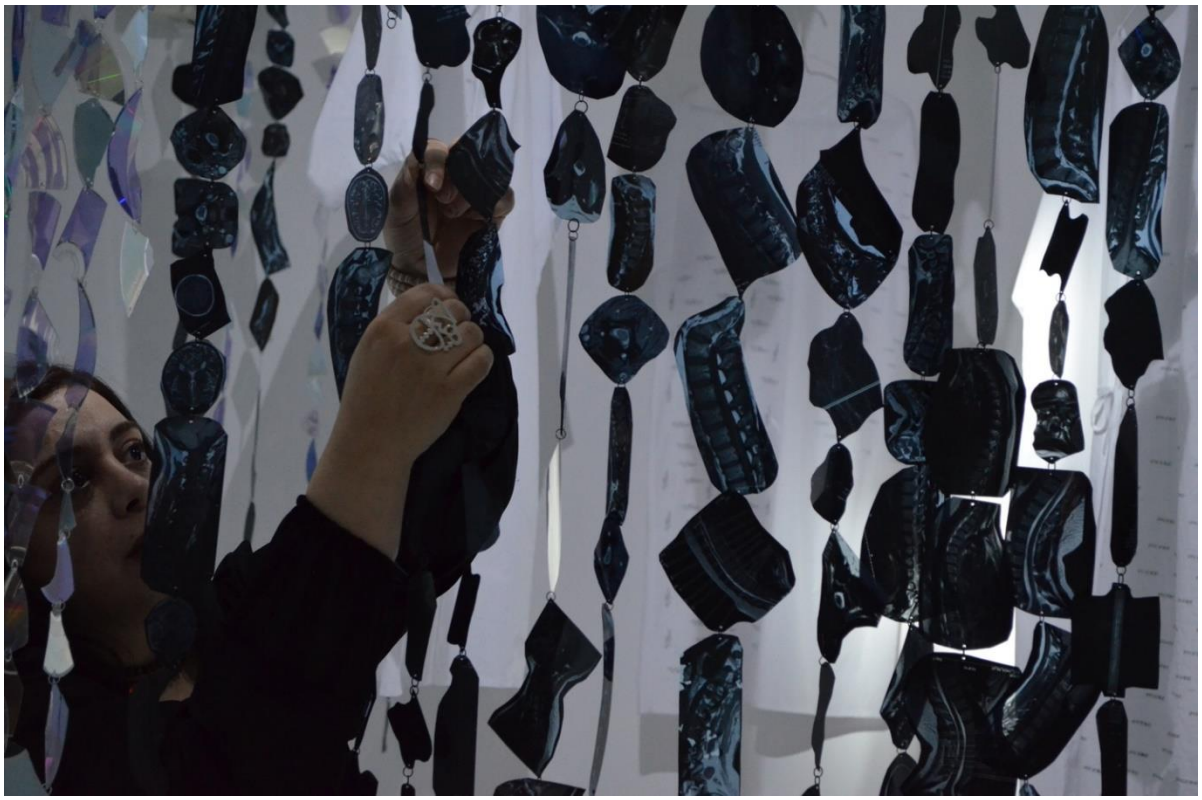


Figure 51: Shattered CDs and cut images - Number 1

Figure 52: Shattered CDs and cut images - Number 2

Figure 53: Shadows of shattered CDs and cut images

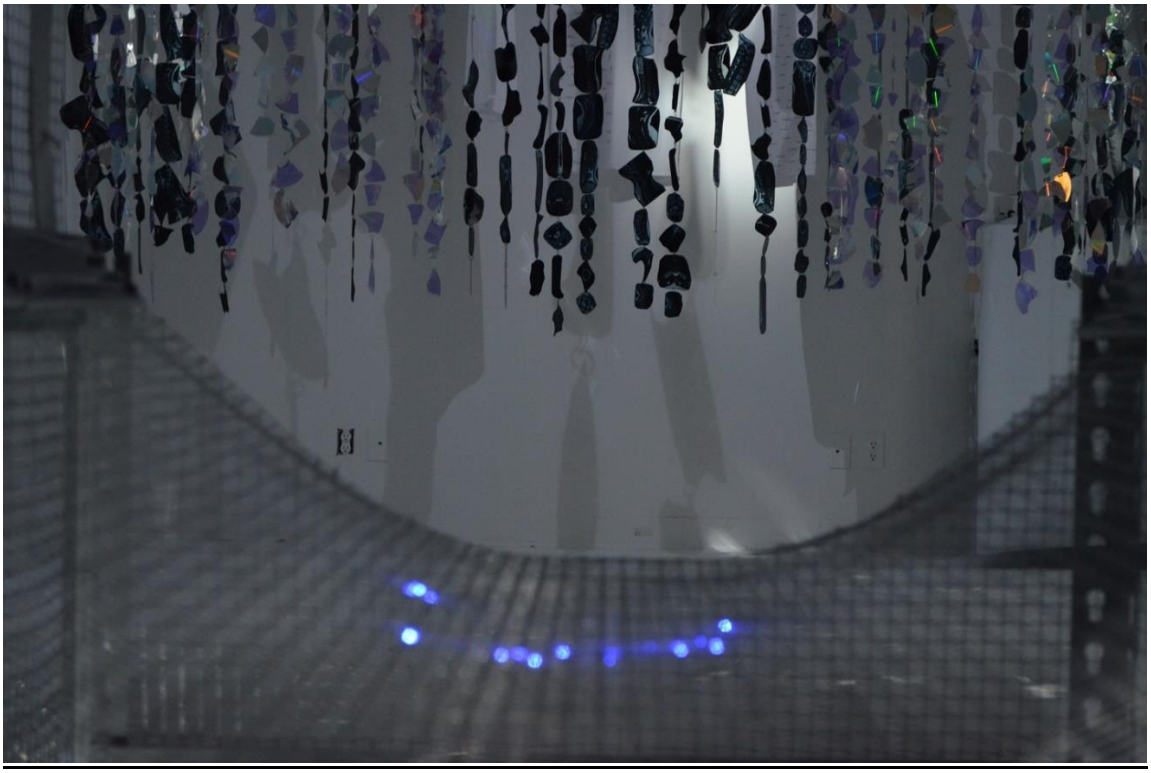


Figure 54: Shattered CDs and cut images - Number 3

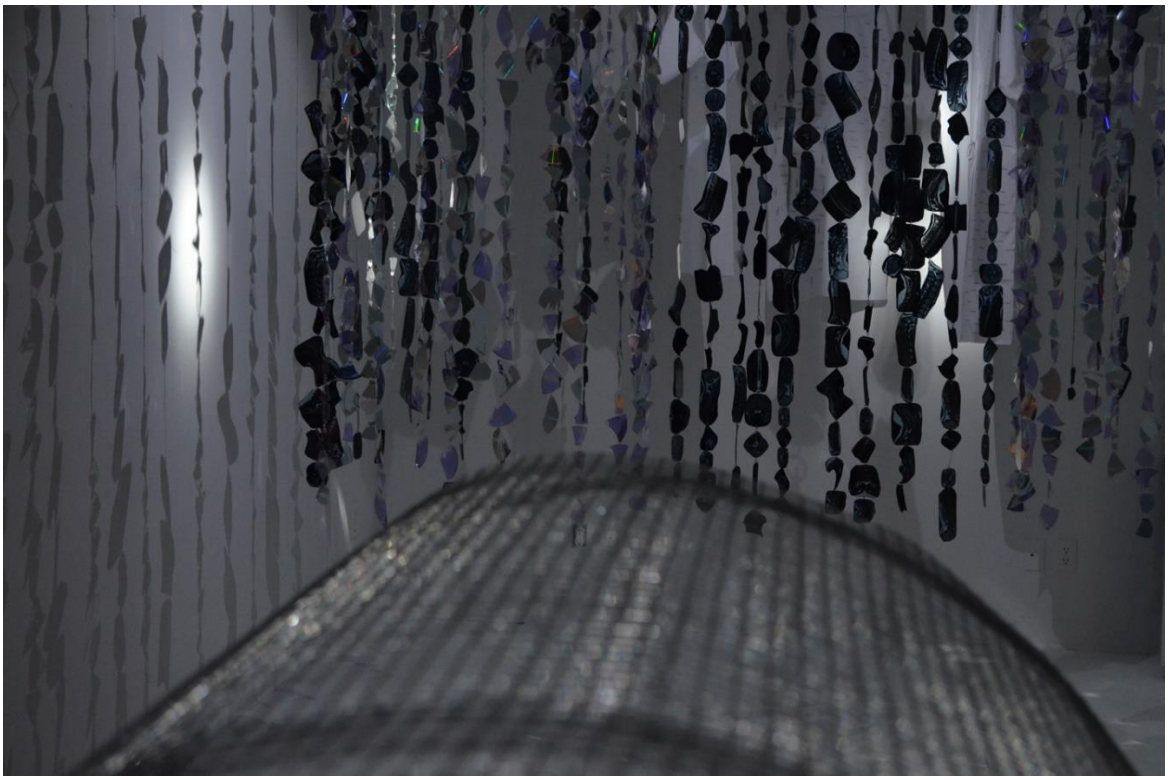


Figure 55: Shattered CDs and cut images - Number 4

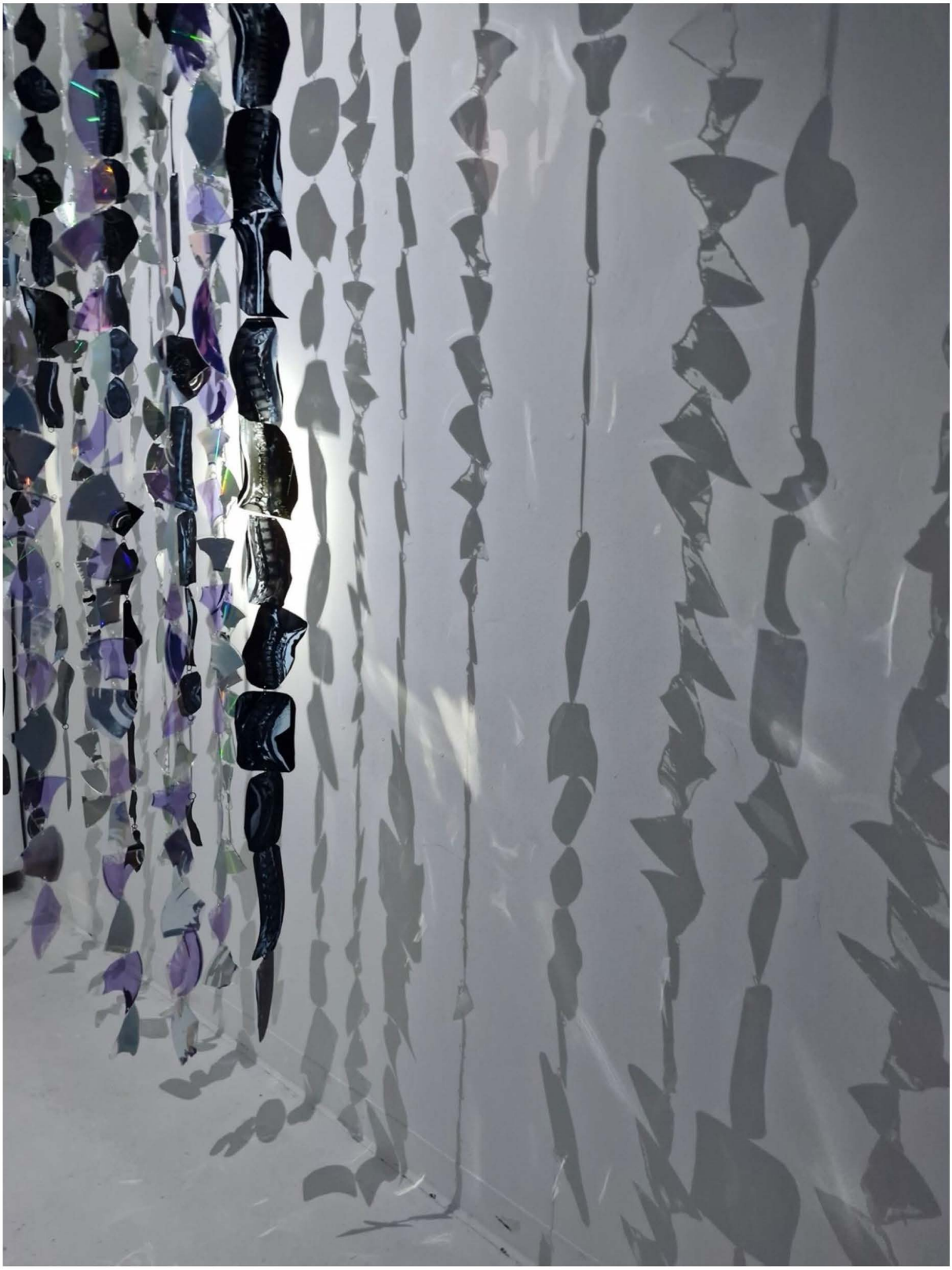


Figure 56: Shattered CDs and cut images - Number 5

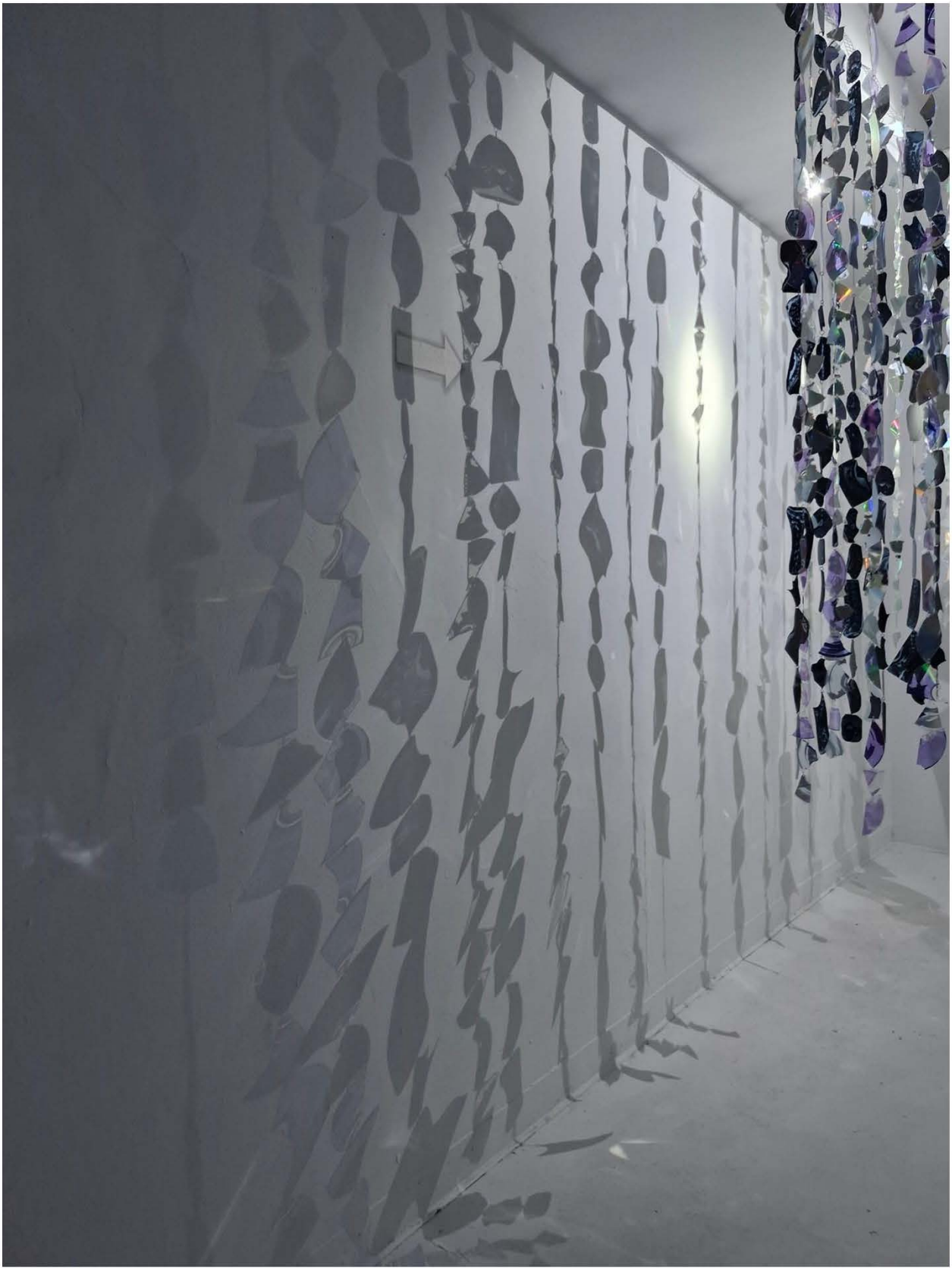


Figure 57: Shadows on the wall

Figure 58: Shadows on the floor

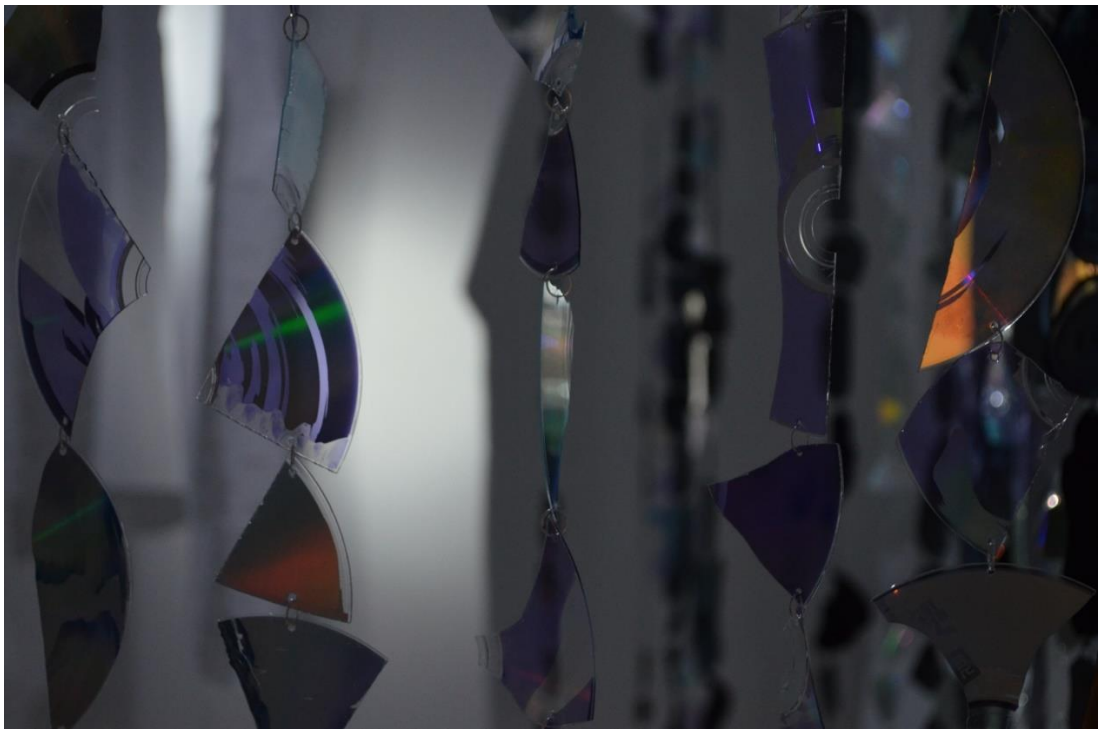


Figure 59: Shattered CDs

Figure 60: Shattered CDs and MRI images (obtained from 50 patients) - Number 1

Figure 61: Shattered CDs and MRI images (obtained from 50 patients) - Number 2

Hospital Gowns with Mark-Making

In this section of the installation, hospital gowns reminiscent of those worn by patients during MRI scans are suspended from the ceiling. These hospital gowns look like ghosts hanging from the ceiling. They represent the tough appointment times and long waits that patients go through, and discomfort inside the MRI. Decorated with the mark-making technique, these gowns visually articulate three significant aspects of the MRI experience: the odd timing of appointments, which can occur late at night or early in the morning; the lengthy waits often endured by patients, which can lead to missed scans due to deteriorating conditions, and the extensive duration spent within the MRI machine itself.

Scattered among these gowns are fragmented MRI images and broken CDs, hanging as if suspended in time, capturing the evolution of medical imaging and patient experience. Occasionally, these gowns catch light that casts hopeful, rainbow-like shadows across them, while at other times they seem to retreat into darkness, symbolizing the fluctuating hopes and despairs of patient experiences. In other words, when light shines on these gowns, it creates hopeful, rainbow-like shadows, but sometimes they merge into the darkness, reflecting the ups and downs of emotions—from hope to despair— that patients feel.

In this section, hospital gowns are displayed alongside MRI images and shattered CDs containing MRI results from various patients. This setup symbolizes the turmoil and desperation felt by many patients oscillating between hope and despair as they seek a path to health and normalcy. For those patients for whom no cure exists, a return to normalcy remains elusive, with their life stories deeply shaped by MRI outcomes. This section also highlights the confusion and anxiety associated with undergoing such tests, the excruciating wait for access, which can extend

indefinitely, and the rigid adherence to healthcare system protocols that sometimes delay timely MRI access.

A personal reflection within this narrative highlights the significant changes in the delivery and accessibility of medical results over time. Initially, medical images were provided as reports, then transitioned to CDs, and eventually, results were sent directly to doctors. This evolution brought two main outcomes for patients: a reduction in material usage and an increased cost if they wished to obtain their own test results, reflecting broader shifts in healthcare practices and patient accessibility. This aspect of the installation underscores the ongoing challenges and changes faced by patients navigating the complexities of medical care, emphasizing the personal and systemic impacts of these experiences.

Figure 62: Hospital gowns with mark-making - number 1

Figure 63: Hanged hospital gowns around MRI results obtained from 50 patients – Number 1

Figure 64: Hanged hospital gowns around MRI results obtained from 50 patients – Number 2

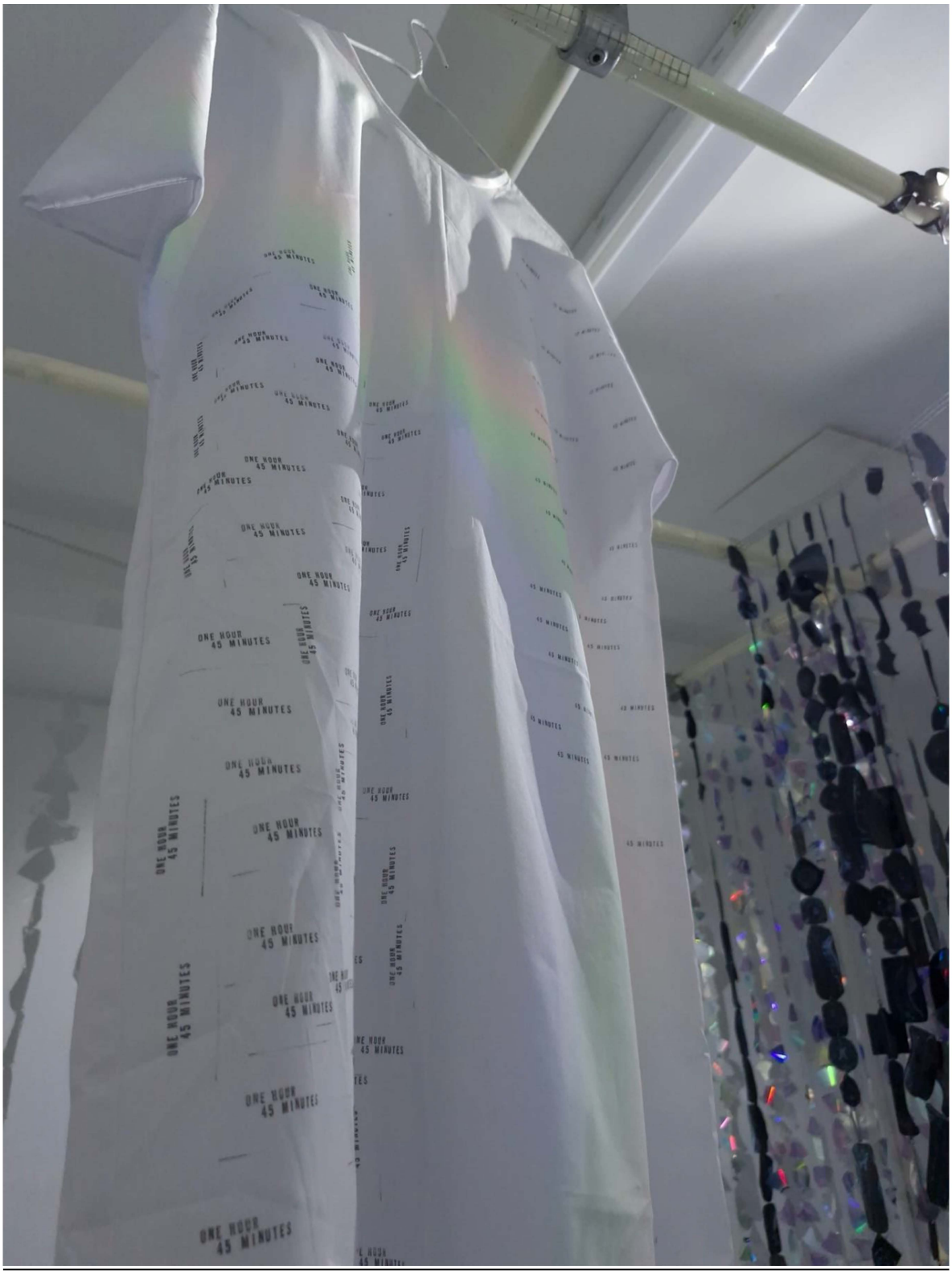


Figure 65: Hanged hospital gown with mark-making - number 1

Figure 66: Hanged hospital gown with mark-making - number 2

Figure 67: Hanged hospital gown with mark-making - number 3

Figure 68: Hanged hospital gowns with mark-making - number 4

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