



Cancer and Caregiving during COVID: A Unique and Horrid Experience

Description

Cancer and Caregiving during COVID: A Unique and Horrid Experience

Author's Memo

I strived to represent the experience of being a pediatric healthcare worker during COVID and also caregiver for my mom. Undoubtedly, the impact of COVID was unrelenting inside a pediatric hospital and for my mother dying of cancer. This work is autoethnographic because I recounted my own experiences and observations. The cultural issue is the impact of COVID on healthcare workers, patients, and also their caregivers.

I have a sense of both pride and grief for my colleagues and my patients. Caregiving during COVID was (and still is) such a unique and horrid experience, and I don't want those moments forgotten. That suffering of patients – and also their caregivers – remains to this day. I don't want that forgotten. I have a sense of determination that this piece of COVID history be documented so the sacrifices, burdens, and intimate sorrows of patients and healthcare workers would not be forgotten. In fact, I recognize that I want to memorialize the healthcare worker experience during COVID. So my hope is I have achieved that.

The reality there was an increase in the number of healthcare workers who died by suicide during COVID, and my place of employment was not immune to that either. I still wonder, almost daily, what allows some to remain on the front lines, some (like me) to step away, and some to kill themselves. That eventually became a central research question in my writings. My data leads me to believe, for me, it was the messages I received from others, and this fits with what I know professionally about depression and suicide.

The AutoEthnographer





Photo of Masks for Covid by Isaac Quesada for Unsplash

Part I: Hiding

September 2020

10:00 am

I can just stay in my office.

I can just sit here all day.

No one will come looking for me.

If someone emails me, I can pretend I am busy.

10:25 am

I have to get out of this office and do my job.

My patients are sweet kids.

Kids with cancer.

They're dying.

Whatever fear I'm feeling,
theirs is a million times worse.

Stop being so selfish.

Don't be such a failure.

What am I so afraid of?

This is my job.

I'm a counselor.

This is my job.

11:15 am

I can just stay in my office all day.

Until it's time to leave

and travel two blocks

to another hospital.

My mom is there.

Unconscious.

Dying of cancer.

11:30 am

Another mobile morgue parks outside my office window.

That makes number 5.

Yesterday it was 3.

Everyone around me is dying.

11:55 am

I just want to stay in this office.

Hide under the table.
A text pops up on my phone.
Another news alert about COVID-19.

I need my Mom.
Her voice.
Her touch.
She'd tell me what to do.

**"I need my Mom.
Her voice.
Her touch.
She'd tell me what to do.**

12:25 pm
I rub the top of my nose.
Gently touch the backs of my ears.
They are sore from double-masking.
I wipe the sweat from my temples.
The goggles make me so overheated.

Just stand up.
Walk to the door.
Turn the knob.
Walk down the hall.
This is your job!
Be strong!

My mom is down the street.
She's dying of cancer.
She is my mom.
I am her caretaker.
I can't save her.

Don't cry again.
Just don't.

2:00 pm
I can just stay in my office all day.
A text pops up on my phone.
My best friend.

Her son has COVID.
She is scared.

3:17 pm

An alert pops up on my computer.
The COVID unit down the hall is full.
They're creating another one.

Just stand up
and leave this room.

Go do your job!

3:40 pm

A text pops up on my phone.
My favorite colleague.
She wants to go home.
I ask what she's doing.
"Laying on the floor in my office not wanting to move," she replies.
I text back, "I'm currently hiding in my office too."

I need my mom.
She is two blocks away.
She is unconscious.
I can't save her.

I can just leave my office.
And go meet with my patients.
We can play a game
while I stay 6' away.
What games can you play at such a distance?

I can see my newest patient.
She will want to hug me.
I will have to tell her no again
and remind her to wear her mask.
How do you tell a child with cancer you can't hug them?

I can just stand up and walk to my office door.
I pause before my hand reaches the handle.
I am scared to see my patients.
I don't want them to die.
It hurts to see them suffering.
What is wrong with me?
I used to be able to do this:
to climb into the trenches and help someone.
Now, I cannot leave my office.

I take another deep breath.
I can just leave this room
and visit the patient I've known the longest...

Part II: Counseling

Characters:

Lisa – pediatric oncology counselor
Xavier – 10-year-old boy with Leukemia

Setting:

Pediatric hospital, oncology unit, patient room

Lisa: (scrubs hands for 20 seconds, puts on fresh mask, puts on fresh goggles, puts on plastic face shield, puts on yellow paper gown, puts on blue gloves, takes a deep breath, and walks into patient's room)

Lisa: "Hey Xavier! Is it okay for me to come in?"

Internal Lisa: Crap I'm already sweating.

Xavier: "Yes Mrs. Lisa, you can come in." (laying in bed, in a hospital gown, his face is pale, his breathing is labored, there are full packets of food on his side table)

Lisa: "I've missed seeing you. I'm sorry I didn't see you last week. I'm so happy to see you today."

Internal Lisa: Oh gosh I am so happy to see him! He makes my heart smile! I love my job! But he looks so pale. He looks much worse than the last time I saw him. I should've been here. Why wasn't I here?

Xavier: "Thank you."

Lisa: (sits in chair that is 6' away from the bed) "How are you feeling right now?"

Xavier: "Horrible."

Lisa: (softens voice) "I'm so sorry Xavier. I know it's so exhausting when you feel horrible. What feels horrible right now?"

Xavier: "My stomach. My head. I've been throwing up all morning. Nothing helps. I want to go home."

Internal Lisa: God, I wish you could go home too. Why are you still so sick? Why do some kids get well and some don't? Please God, don't let him die. Please.

"Please God, don't let him die. Please."

Lisa: "I know you do. I want you to go home too. I'm so sorry you're still here at the hospital. Can I hold your hand?"

Xavier: "Yes... please."

Internal Lisa: I hope this helps. I have learned it's these little things that seem to bring comfort when there are no words. I wish I wasn't wearing a stupid PPE glove. This is so not therapeutic to hold his hand with a damn glove.

Lisa: "What would you like us to do today?"

Xavier: "I don't know. It doesn't matter."

Lisa: "I could give you some ideas? Let's see... We can do a relaxation exercise. All you need to do is lay there with your eyes closed and listen while I talk. Or, we can play UNO again. (softly smiling) I'm pretty sure I need vindication after you beat me last time. Or... we can listen to music? Or... you can talk and I can listen. Hmmm do you want to do any of those things?"

Internal Lisa: Why did I say we could play UNO? That's against COVID policy. I didn't even bring the cards. I'm not even supposed to hold his hand. I'm supposed to stay 6' away. We can't listen to music either- I'm not allowed to bring my phone in anymore. I know the risk. I could have COVID and if I do, I could kill this sweet little boy. Oh my god if he dies it will kill me.

Xavier: "We can talk."

Lisa: "Okay cool! What should we talk about?"

Xavier: "I like when you ask me questions."

Internal Lisa: Please don't die. This isn't fair.

"I'm supposed to stay 6' away. We can't listen to music either- I'm not allowed to bring my phone in anymore. I know the risk. I could have COVID..."

Lisa: (laughs) "Really? You mean you aren't tired of all the millions of questions I ask you?"

Xavier: (soft smile) "No, I like it."

Lisa: "Okay, well let me think. Let's start with our usual questions: What is the worst thing about today? What is the best thing about today?"

Xavier: (thinking silently) "The worst thing about today... is... I'm throwing up and I want to go home. Um. The best thing about today is... my Mom said... I might go home soon."

Internal Lisa: His mom is trying to give him hope. He can't go home until he shows his doctor he will eat again. Or when he gets a feeding tube. He refuses to eat, and I don't blame him one bit. He said everything tastes like metal. Everything gets thrown up. Just like my Mom these days. Stop thinking about your Mom. I'm supposed to convince Xavier to eat something. As if counseling is magic.

Lisa: "Ahhhh that does sound like a great thing – to go home soon. What is the very first thing you'll do when you get home?"

Xavier (thinking quietly) "Hmmm. Hug my dog. I bet he misses me."

Internal Lisa: (begins sobbing uncontrollably and invisibly)

Xavier: (sits up and begins vomiting)

Internal Lisa: Shit! Shit! Shit!

Lisa: (holds blue bag under Xavier's bottom lip with one hand, holds his hand with the other)

“Xavier: “Why is this happening to me?”

Lisa: “It's okay Xavier. I'm here. Let me see your eyes? (we make eye contact) I'm here. This will pass.”

Internal Lisa: Don't cry. I held this bag for my Mom. All

those times. She was so sick. I was so scared, couldn't do anything to help her and can help Xavier. I can do that.

Xavier: (spitting vomit into the bag) “Mrs. Lisa?”

Lisa: “Yes?”

Internal Lisa: This sweet boy. I care for him so much. I wish I could make his pain go away.

Xavier: “Why is this happening to me?”

Part III: Rushing

September 2020

I am rushing home.

To shower, change clothes, eat something.

Then return to the hospital.

Not the one I work at.

The one where my mom is dying of cancer.

Abruptly, I stop at the front door when I remember...

“My birthday is this weekend,” I tell my husband.

“My mom's not going to die on my birthday, right?” I ask him.

Like any good husband, he replies in the only way he can,

“No, your mom is not going to die on your birthday.”

I can keep going.

No, I'm not hungry.

No, I'm not tired.

I can keep going.

Earlier at work, we were told we must see our outpatients virtually.

With something called Zoom.

Because COVID policy restricts visitors of any kind.

Most insurances don't cover virtual counseling.

What happens to those patients?

They must be discharged from my care immediately.

And for the first time, I understood what moral injury means.
But now it is time to see my Mom.
I am her only visitor.
The only one allowed.
Each day my temperature is checked.
It is marked on a sticker that is placed on my shirt.
My name is checked on a list.
And I hold my breath, hoping they will let me in.
Hoping a new policy won't prevent me from seeing my mom.

“Hoping a new policy won't prevent me from seeing my mom.

I walk quickly down a long hallway, taking two different elevators,
to the back of the hospital where hospice is located.
I hold my breath, hoping my mom has not died yet.
Hoping I can see her again.
Hoping I can hold her hand
and watch her peaceful face
as she breathes slowly in and out,
as I gently lay my head against hers,
and wonder if these are her final breaths.

When my mom's cancer returned, we had a plan.

The next week the world was introduced to COVID-19,
and the medical community declared that my mom's life was no longer worth saving.
Her treatment stopped.
Her surgery was cancelled.
They had to make room for all of the COVID patients.

I replay the phone call from her oncologist over and over in my head: “I'm sorry Lisa but your mom's treatment and surgery have been canceled. I even presented her case to the tumor board, and they denied her treatment. Let's just wait and see. This pandemic should be over in a couple months.”
Nothing I said could convince him otherwise:
“Please don't let my mom die. Please.”
and
“I need you to understand something: I will NOT allow my mom to die of something that is treatable because there is a stupid pandemic going on!”
My mom's life no longer mattered to the medical community. It still matters to her. It still matters to me.
Does anyone care?

Act IV: Sinking

Characters:

Max: Lisa's cousin, same age, more like a brother

Lisa: Pediatric oncology counselor

Setting:

Adult hospital 1 & Adult hospital 2

Today is Max's birthday. One month after mine. He loves birthday phone calls.

I move to the armchair besides my mom's bed.

I call him. Straight to voicemail. That's so not like him...

Max.

My cousin who stands at 6'4" to my 5'3". He outweighs me by 200 lbs. His laugh is boisterous and loud – too loud – and it always feels like home. When my family was broken, he was there. Ready to talk, laugh and quote his favorite lines from his favorite movie "The Goonies".

Max.

I was at his side

as he sat at his mom's side

while she died from early-onset Alzheimer's.

Lisa: "How are you handling this and being so strong through all of it?"

Max: "We're strong for each other, right? That's what keeps me strong."

One late night, after visiting his mom at the memory care center,

I was just dozing off on his sofa while he sat in his big comfy chair.

We were mid conversation when I fell asleep.

Max: "My mom is going to die soon. Then, I will have no one. I don't have a wife or a dad. You have your husband. You have your mom. Everyone has someone. I'm alone."

"There is no answer.

There are no fucking answers I can live with.

I will have to choose.

Fuck every fucking thing in this universe, I am going to have to choose.

The next morning I uncharacteristically awoke with the sun and with a startle.

I marched over to his room and knocked loudly on his door.

Max: (half-asleep, laughing) "I'm sleeping! Go away!"

Lisa: (yelling at the closed door) "Max! Listen to me! Don't EVER say you are all alone ever again! Do you hear me? I am here. You have me! I will always be here for you!"

Max: (laughing sleepily) "Thanks sweetie."

"Now let me sleep!" (yelling and laughing)

But that was two years ago.
Today my mom is in hospice.
Max's mom is dead.
And I haven't spoken to him in weeks.
I move back to my mom's bed.
I lay my head down beside her head,
I listen to her uneven breaths,
and I think: I'll try calling Max again tomorrow.

Tomorrow

I look at my phone and study my texts to Max. I scroll through my one-sided messages and realize he has not responded to me in weeks.
How did that happen? How did I let that happen? What day is this again?
Something is wrong.
I text my Uncle Manuel who is 12 hours away. We have talked every day since my mom's cancer returned. But he hasn't said anything to me about Max.

This time, he tells me:

"Max is in the hospital, sweetie. No one wanted to tell you because of what you're going through with your mom. He is dying. He is going to die. You can call the nurses' station at the hospital, and she can put you on speakerphone. I know he wants to hear your voice one last time."

I don't even have a reaction.

I put the phone down and stare at the wall.

This isn't real.

It just isn't.

No way are my mom and my cousin-more-like-brother both dying at the same time.

Is it real?

I am catatonic.

I am silent.

It's just me and the incessant ticking of the clock on the wall.

Nothing is real.

Max is at a hospital 4 hours away.

I could drive there.

I need to see him.

I promised him I'd be there for him.

I discuss this with my husband.

Lisa: "What if Max dies while I'm here with my mom?"

Could I handle that?

Lisa: "What if I leave to visit Max and 3 hours into my drive my mom dies?"

Could I handle that?

There is no answer.

There are no fucking answers I can live with.

I will have to choose.

Fuck every fucking thing in this universe, I am going to have to choose.

“I am catatonic.

I am silent.

I call the nurse's station.

I don't recognize my voice.

I don't know what to say.

I am underwater.

I am sinking.

Sinking.

And I don't even care.

The phone call

Max (barely audible): Hello?

Lisa: Max? It's Lisa.

Max: Lisa.

Lisa: Yes... I've been trying to reach you for weeks... Uncle Manuel just gave me this number. Are you... are you okay?

Max: I'm dying...

Lisa: Max...

Max: They said I'll die in the next couple of days.

I am sinking.

Sinking.

Lisa: Max... I... do you... what do you need? What can I do for you?

Max: (crying) It's so lonely here. It's just so lonely. I'm in a hallway. There are no rooms. There's a whole row of us in the hallway...

Lisa: Max... I'll come see you. My... um, my mom is in hospice. That's why I haven't come to see you yet. I'm so sorry. I will come see you, okay? I can be there soon, okay?

Max: (muffled) How are you doing?

I am sinking.

I can hear him drowning.

Say everything you need to say.

Lisa: Max... listen... thank you for being my big brother... you're the best brother I've ever had... I love you so much and... I don't know what I would have done without you in my life.

Max: ...I love you too.

Nurse in the distance: I have to end the call now. I'm sorry Max. I'm sorry.

Lisa: Max! I love you, okay? I'll see you soon, okay?

Call ends.

Sinking.

The light from above disappears.
Darkness surrounds me.
Murky water that is warm like a blanket.
I let myself sink.

As soon as the call ends, I am catatonic.
My eyes are dry.
I stare at nothing.
No.
How.
Why.
And I lied to Max.
I won't go see him.
I won't leave my mom.
I knew it the moment I said it.
He will die alone in a hospital hallway, and I won't be there.
He will die alone.
I blink.
I wish it was me.

I am angry.
The fire I feel in my body could burn a forest down.
I am so angry.
At COVID.
At people who say it isn't real.
At God.
At myself.
I hate cancer.
I hate COVID.
I hate hospitals.
I hate myself.
I failed everyone.
I am... unforgivable.
I deserve whatever happens next...

I will never see Max again,
hear his boisterous laugh,
or feel his big bear hug.

Instead,
I will get a text message less than 24 hours later.
From another cousin...
"Max just died.
I'm sorry.
I know you're with your mom
but I know you wanted to know."

I will stare at my phone.
I will read the text over and over.
It isn't real.
This isn't real.

I will lay my head down beside my mom, as she slowly dies here in hospice.
I will close my eyes and listen to her uneven breaths.
I will whisper, "Mom...Max just died."

Part V: Endings

October 17, 2020 – my mom's birthday –

She has been unconscious in the hospice unit for 17 days now. I had a weird feeling she was holding on for her birthday.

Every day this week, I give her a present that I order from Amazon Prime. Today's gift is a soft and fluffy blanket that says "Mother". I kiss her forehead and tell her, "You did it mom! Happy Birthday!" I spread the new blanket over her and tuck it gently under her chin.

Her 2 best friends call my cell. They are downstairs outside the hospital's main doors, have brought her flowers and birthday balloons and know they can't come inside and see her – because of COVID protocol. They want me to give her the flowers and balloons.

I went downstairs to see them. We hugged and cried. With masks on. We recorded ourselves singing Happy Birthday to my mom. We hugged and cried. With those stupid masks on.

When I got back to her room, I told her about the vases of flowers and balloons from her best friends. I hoped she could smell the flowers, tied the balloons to her bed and played the recording for her over and over. I had to stand at the window with my back to her so I could silently cry in anguish.

"October 21, 2020

2:20 am

My mother has died.

Everything has stopped.

October 21, 2020

2:20 am

My mother has died.

Everything has stopped.

I knew it was coming, and it was still a shock.

I still covered my mouth to silence the scream.

For days I had whispered into her ear that it was okay to let go.

"When God calls you,

you can go.
I promise I'll be okay," I told her.
Our last conversation, I did all the talking.
She awoke in a panic, eyes bulging in terror.
"Mom," I said gently.
Her eyes looked at mine and she smiled in relief.
So much relief washed over her face when she looked at mine.
She spoke with her eyes, her face, and her smile.
She said so much to me without using any words.
I told her I was sorry I couldn't save her from cancer.
I told her she fought so hard,
for so long.
"It isn't time to fight anymore," I told her.
"It's time for us to let go."
"I'll never let anyone say you lost to cancer," I told her.
"Because you didn't.
You beat cancer in the way you lived your life, mom.
You never lost your faith, your joy, your sense of humor, and your love for others.
You beat cancer because you did not let it destroy who you are."

She blinked and smiled softly.
Then she closed her eyes.
And I waited for her body to die.
It was cruel.
They call it "a good death."
Because she is not alone
and she is not in pain or distress.

But it is cruel to watch
and to know you are allowing it to happen.
"There is nothing else to do for her now,"
said all the doctors, nurses, chaplains, social workers, and administrators.
I asked them all.
I was her caregiver.
It was my job.
When she quietly slipped out of this life,
I broke into a million pieces.
I had walked her to the furthest edge of this life,
as far as I'm allowed to go.
And I knew in that moment,
it was the greatest blessing and curse
to have been her caregiver.
I own the mistakes.
I own the second-guessing.
I own all of the what ifs.
I clean up the mess left behind.

When cancer attacks your family,
everyone tells you to “fight.”
Where does all that fight go when your loved one dies?
It is still alive and raging inside of me.
The next day, I get an email.
One of my patients died.
She loved talking about her dog.
I didn’t get to say goodbye.
I say her name out loud to any empty room.
I want to hear it one last time.

12:00 pm
I have slept for 10 hours.
I had not slept in weeks. Months?

I get to stay home for 2 days, and then return to work.
I discover I cannot have an autopsy done on my mother.
The backlog is 2 months, maybe more, because of COVID.
I think of her body kept frozen in a cabinet drawer for 2 months, and I can’t.
I cannot send her body to the place she always
wanted to be her final resting place,
beside her own mother,
because there is a backlog of several months, because of COVID.
I think of her body kept frozen in a cabinet drawer for several months, and I can’t.
Her funeral is livestreamed.
It is too dangerous for people to attend in person.
I see one of my oldest friends.
She is crying behind her mask.
I am crying behind mine.
And I can’t hug her.
I cannot hug everyone who arrives to grieve for my mom.

“We have to follow COVID safety protocols and we ask that no one approach the family,” is announced
to everyone in attendance.
It is salt in the gaping wound of grief.

Grief needs comfort, support, to be seen and heard and witnessed.
To gather and share stories, laughter, and tears.
Mine hides behind a mask.
Because someone could get COVID at her funeral and die.
I will return to work next week.
How will I ever help another person again?
I couldn’t help my mom.
My oldest friend calls me.
“Your job was not to save your mom from cancer,” she tells me.
“It was your job to walk alongside her during cancer

and help her feel safe and loved.
You did that.
You did your job.”
I write down her words.
Because I don't believe them.
I will read them every day until I do.

Part VI: Drowning

January 2021

I just finished my weekly counseling session.
The one where I am the patient not the counselor.
The day after my weekly virtual grief support group.
People in the group share happy memories of their loved ones.
One other girl and I just cry.
People in the group can't bear to drive anywhere near the hospital where their loved one died.
They all agree on this.
No one can do it.
It is much too painful.

I can see the stupid hospital where my mom died from my office window.
I have to drive by it every day to get to work.

I can't really help anyone, no matter what I do.
Helping people is my job.
It has been my job for 19 years.

**“Everyone is drowning.
Everyone is trying to swim ashore
and save everyone we see along the way.**

My coworker is crying in the stairwell.
I have no words of comfort.
Another coworker is living in a hotel.
She does not want to get COVID at work and give it to her family at home.
The entire hospital campus is cloaked in a very heavy sadness.
I see it in the eyes of every person I pass.
Everyone is drowning.
Everyone is trying to swim ashore
and save everyone we see along the way.

I check my email.
There is a new death announcement.
Another colleague killed himself.
No.
How.
Why.
I have to leave this office.
I have to get outside.
I think of him walking this campus.
I wonder how many times he walked these steps.
I think of how many times I have walked these same steps and cried.
I wonder what it is that separates him and I.
Counselor voice: Depression is a liar.
That's why isolation is so dangerous.
If the only message you are hearing is the negative self-talk in your head, you are only hearing lies.
The lies tell me: you are not good enough,
you have failed everyone,
you cannot handle this,
this is never going to get better,
you're the only one feeling this way,
you let your mom die.
And then the bargaining begins...

The AutoEthnographer

Just let me die, and maybe that will allow someone else to live.
Someone who deserves life.
Someone who isn't failing and letting everyone down.
I am a burden, and they will be better if I am gone.
Counselor voice: That's why isolation is so dangerous.
A depressed mind is like a bad neighborhood.
You don't want to walk through it alone at night.
You must connect with others.
You must talk with others
who care about you.
Only then will you hear messages that contradict the lies in your head.
"I think you're very brave."
"You're showing up every day and that matters."
"I am glad you're here."
"I don't think you're failing anyone."
"What if your 50% is better than most peoples' 100%?"
"I'm downstairs. I brought you dinner. Can you come down for a few minutes?"
"Thank you for being my guardian angel."
"It's okay to rest."
"I am afraid too."
"I'm struggling too."
"We are doing our best."
"We will get past this."
"We will."

My only shelter: the words of the people who love me.
When I walk this campus, I think
how many times has someone said something to me that contradicted the negative self-talk in my
head?
How many times have their words stopped me from crossing over to the same place where my
colleagues thought they had to kill themselves?
How many times has someone's kindness saved me?
I will never know.
But I can imagine.
And I think of my colleagues.
Reading the email death announcement today.
Fighting this battle.
Together.
And all alone.
The intensity of the feelings of loss, of grief, of fear, of loneliness, of powerlessness...
It is all I feel.
Suffering is all around me.
Suffering is all that is inside me.

I want to stand in the middle of the street and scream.
I want my mom.

I don't know how to be me anymore.
I failed as a daughter.
I am failing as a counselor.
I am failing as a wife and a friend and a coworker.
I can't live like this.
This must end.

I think I am going to leave my job.

Part VII: My Job

February 2021

I have learned to make a joke of myself.

"It's not helpful if the counselor is the most depressed person in the room," I say.

It makes people laugh.

And I laugh too.

Because it's true, and it hides my shame.

My patients are getting sicker.

Their sadness,

loneliness,

boredom,

and isolation

are painfully heavy.

Their families gather in the parking lot holding up signs.

Because they are not allowed inside.

"HAPPY BIRTHDAY!! WE LOVE YOU!!!" reads a sign held by my patient's father.

Can I trade places with him so he can be in here with his son?

He needs his dad more than he needs a stupid counselor.

No one taught me how to endure the guilt I feel in this moment.

No one prepared me for it.

I carry it alone.

And if I could, if only... I would trade places with every mom and dad and sibling and best friend who has to facetime my patients from the parking lot.

**“Their sadness,
loneliness,
boredom,
and isolation
are painfully heavy.**

My mom – she needed all of her friends and all of her family at her side as she died;
not saying their goodbyes on speakerphone while she lay in a coma.
She needed to hear stories, recount memories, laugh, cry, grieve, and hope.
She needed to hear “Thank you Maggie” over and over and over.
COVID took that from her.

And it can never be given back.

2:20 am

I am sitting on the floor in my bathroom.

I can just sit in this room all night.

I don’t recognize the world anymore.

And I can’t do anything to fix it.

I am a helper.

And

I

am

helpless.

It hurts to stand.

It hurts to breathe.

It hurts to see my reflection

and know I can’t help anyone.

And I think: I can just stay in the bathroom all night.

A text pops up on my phone.

It’s from my husband who is on the other side of the door.

“I love you,” it says.

“It was never your job to save your mom.

It was never your job to save your patients.

But it is your job to save yourself.”

I stare at the words.

I read them over and over.

I blow my sore nose and rub my throbbing head.

The words begin to sink in.

Part IX: The Gift

I have been told to clean out my mom’s apartment.

How can I?

Every inch of this space holds a memory – good and bad – that I will never forget.

Her scent is everywhere.

I want to leave everything as it is.

I touch the soft fabric of her comforter and

I want to memorialize it all...

Here lies the last place Maggie lived. She lived a good life, cared for others and loved having friends over, laughing, and going to church. She was going to beat cancer. But COVID happened, and they stopped her treatment. She did not want to die.

I give myself 20 minutes.

Take everything I want.

My husband and my mom's friends will do the rest.

The rest I cannot do.

I won't.

Quickly.

Don't think.

Don't cry.

Be strong.

Deep in a cabinet I find a bag that makes everything stop.

It is a bright purple gift bag with purple glitter tissue paper.

Without thinking I open the gift.

It must be from one of her friends? I think.

Inside is a small white box.

I open the box.

Whatever is inside is wrapped in bubble wrap.

I tear open the bubble wrap.

“A lovely gesture.

It's a music box.

It's silver and ornate

and on the front,

it is engraved with these words:

She believed she could, so she did.

And I roll my eyes.

It must have been from one of her friends

to help her get through cancer.

A lovely gesture.

But I react in anger.

She believed she could beat cancer and it didn't matter!

She still died!
So a lot of good this stupid...
then I see the music box is engraved with something else.
To my Lisa
That's my name.
I read my name over and over.
This gift is... for me?
She got this... for me?
When did she buy this?
And wrap it?

She was too sick. She was in and out of hospitals for months.

I search the rest of the bag for a receipt.
I search the box for a shipping date.
Nothing.

She believed in me more than I believed in myself.

She must have bought it months ago.

She got this for me.

She had it engraved with my name.

She wrapped it.

And she wanted to give it to me.

She had stopped speaking when they told her it was time for hospice.

But she knew.

She knew everything...

The realization of what she knew, what she endured alone, what she hoped for, and what she knew she'd leave behind – it all hits me as I slide to the floor beside her bed.

“The realization of what she knew, what she endured alone, what she hoped for, and what she knew she'd leave behind – it all hits me as I slide to the floor beside her bed.

I turn the little nob inside the box.

One, two, three, four, five times.

The music begins.

Just a piano melody.

But I know the words.

I know the song instantly.

For the first time in weeks, I come up for air.

I will treasure this forever.

I close my eyes while I rest my head against her bed,
I listen to the music,
and I whisper, "Thank you Mom."

Epilogue

I have put away my counselor hat.
I wore it for 20 years.
My patients deserve a counselor who is not broken.
It is the right and ethical thing to do.
It is an excruciating thing to do, and I am covered in guilt.
To walk away from my colleagues who are still in the trenches.
To a harbor nowhere near the war they continue to fight.
Every week, I stand at my mother's grave and apologize.
"I'm sorry, Mom. I'm so sorry I couldn't save you."
I have accepted a new position at work.
I will work from home where the view outside my window is a rose bush
not another hospital, not a mobile morgue.
It is where my husband works down the hall from me,
and where our dogs bring me tennis balls in between zoom meetings
I will continue weekly counseling
and grief support group.
The ones where I am the patient.
I will keep talking about my feelings,
making sure they do not stay in the dark,
even though they are covered in shame, I will speak them.

"I will keep talking about my feelings,

I will forgive myself.
I will give myself permission to stop and rest.
I will grieve...
for my mom,
for Max,
for my colleagues,
for my patients who died,
and the patients I left behind,
for the career I left behind,
for this world I still do not recognize.

I will sleep,
eat,
walk the dogs,
go for a run, and
laugh at something funny.
I will learn to do all these monotonous things again
without breaking down in guilt-ridden tears.
I stand on my concrete patio,
my dogs close by my side.
I think of the concrete path around the hospital
and I know I will not return.
I see the scenes of this year float by me,
Like dark gray clouds in the sky.
They have lingered for so long.
I watch each one pass overhead.
I see each cloud.
Each cloud sees me.
And I watch them pass by me.

I do not know what is on the other side of this bend.
I cannot see more than a few steps ahead of where I am.

But I do know this:
I will help myself.
I will take care of myself.
I will save myself.
It is my job.

Credits

Photo of masks for Covid by [Isaac Quesada](#) for [Unsplash](#)

Featured Image of a map showing the Covid density by [Martin Sanchez](#) for [Unsplash](#)

Learn More

New to autoethnography? Visit [What Is Autoethnography? How Can I Learn More?](#) to learn about autoethnographic writing and expressive arts. Interested in contributing? Then, view our editorial board's [What Do Editors Look for When Reviewing Evocative Autoethnographic Work?](#). Accordingly, check out our [Submissions](#) page. View [Our Team](#) in order to learn about our editorial board. Please see our [Work with Us](#) page to learn about volunteering at *The AutoEthnographer*. Visit [Scholarships](#) to learn about our annual student scholarship competition.

Category

1. All Content
2. Autoethnographic Poetry
3. Autoethnographic Writing
4. Volume 3, Issue 2 (2023)

Author

Inichols4

The AutoEthnographer