

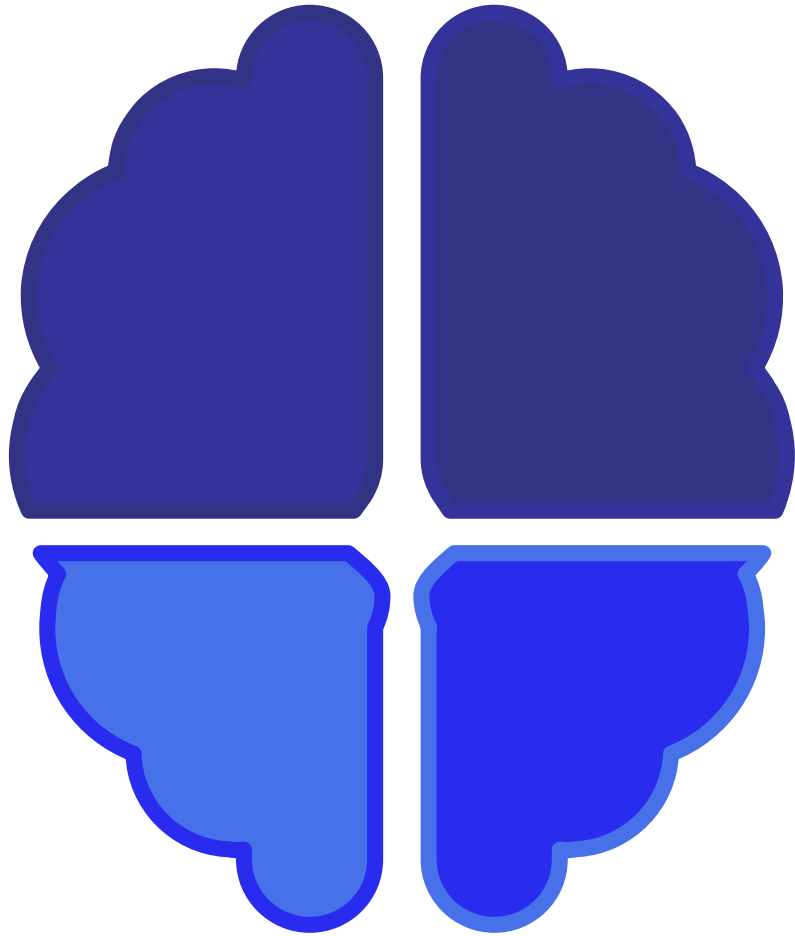
# Neuro Narratives

experiencing resilience  
with a brain tumor

Christina Costa



# Agenda



01

My Background

02

Resilience Research

03

Methods & Results

04

Q&A



# My Story







19

November

Migraines = Tylenol



20

April

+Fainting feeling + 28 calls to Neurology Dept.



20

January

+Blurry Vision = Tylenol + Eye doctor



20

June

+seizures + portal message to Neurology = Neurologist appointment in early July



20

March

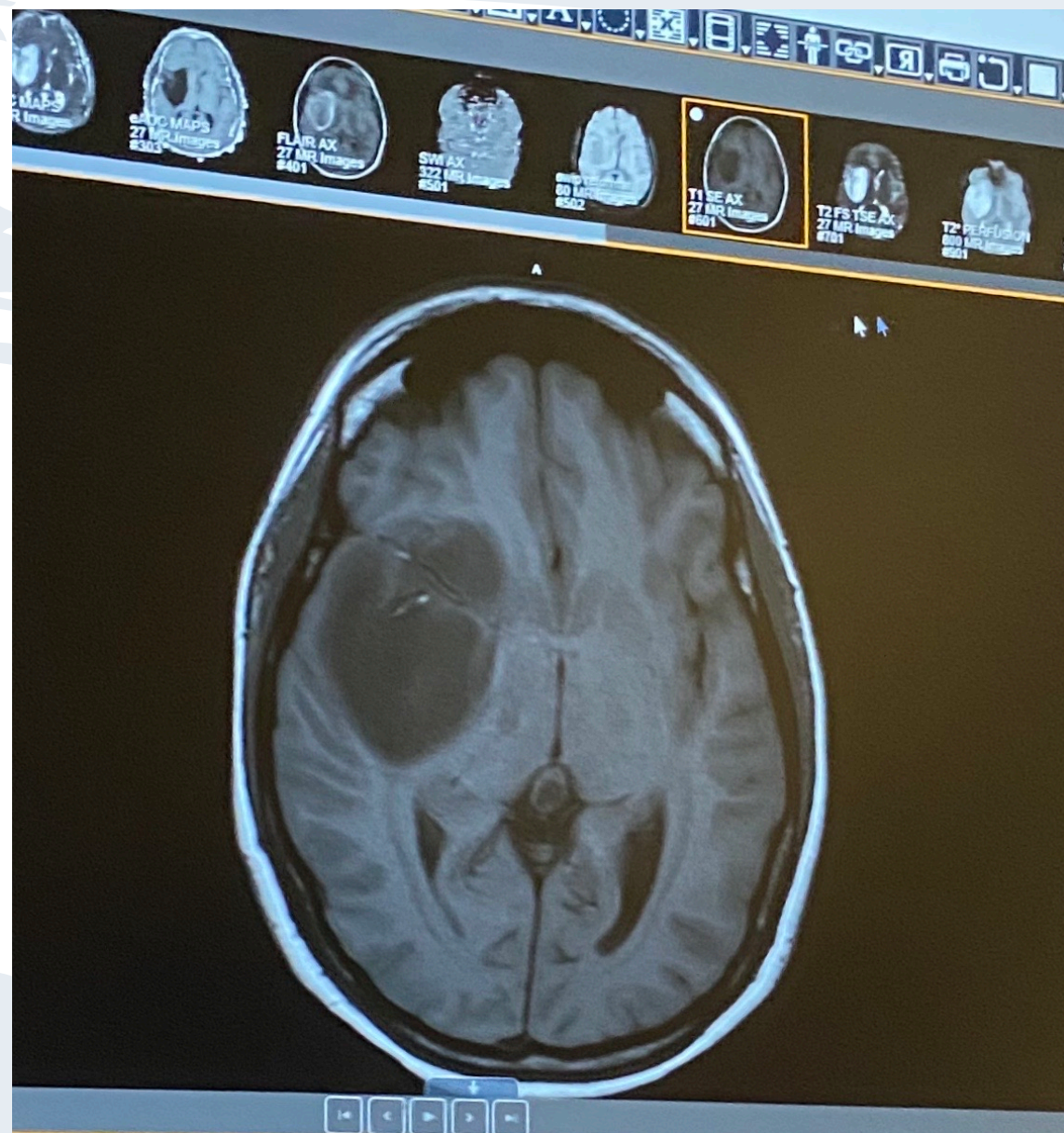
+Left side numbness = Referral to neurologist for Nov



20

July

MRI is ordered, called in to emergency room



# Treatment Plan

## August 2020

---

- MRI, fMRI, appointment with Neurosurgery
- Surgery Consent

## September 2020

---

- 13-hour awake craniotomy with safest total resection
- Pathology: Anaplastic Astrocytoma G.3
- Meet with Neuro-oncology
- Embryo preservation

## November 2020

---

- Egg retrieval
- MRI(s)
- Radiation simulation



## Jan-Feb 2021

---

- Chemo-radio Therapy

## 2021-22

---

- 12 rounds of chemo
- MRI, wait, repeat

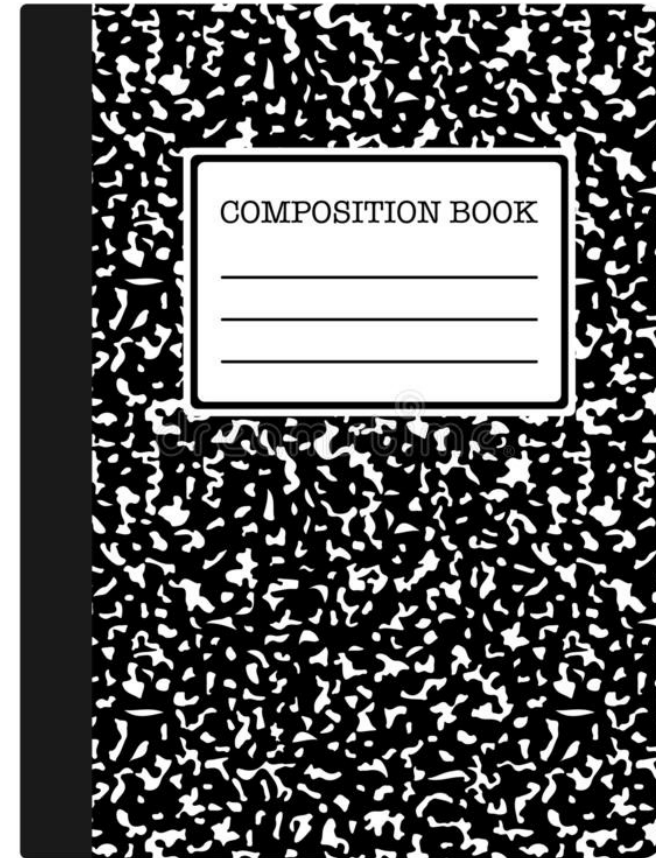
## **My Brain**

She is beautiful  
She is powerful  
She is intelligent

She has a trespasser  
That is not welcome  
That came without permission  
just like so many other things  
we don't expect in life

But she is brave  
and even though she is scared-  
she will face the unexpected

She is resilient

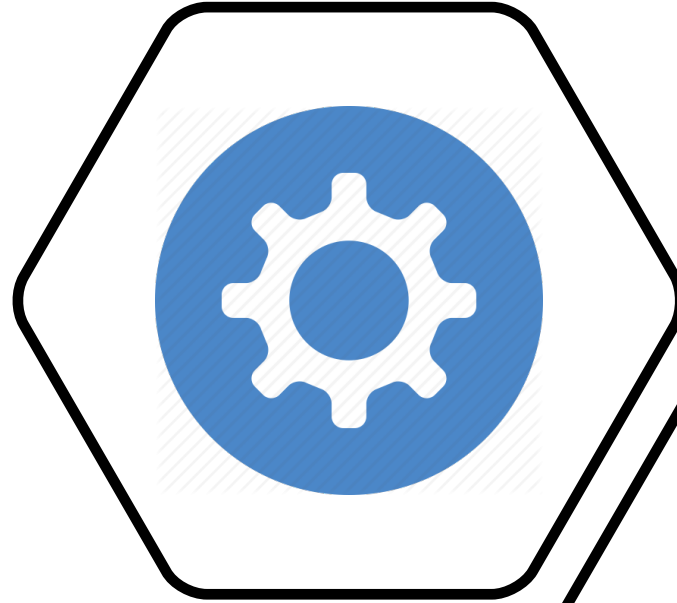
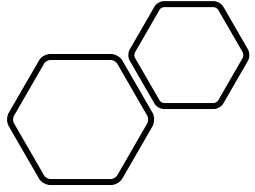




# Research Questions

- How did I adapt to a change?  
/ How do cancer patients adapt to life-threatening changes?
- What factors helped me survive & thrive? / What factors help oncology and chronically ill patients survive & thrive?





# Method

- Day of diagnosis to completion of treatment round 1 (approximately 6 months)
- 124 poems
- Context of poetry
- Autoethnography





# Resilience Research

# Defining Resilience

- Resilience enables people to survive, and even thrive, in the face of adversity<sup>1</sup>
- Historically, most research focused on negative outcomes of adversity
- Resilience research seeks to understand how individuals thrive despite the difficulties they face



resilience, joy, engagement

stress, anxiety, burnout



# Cancer and Resilience

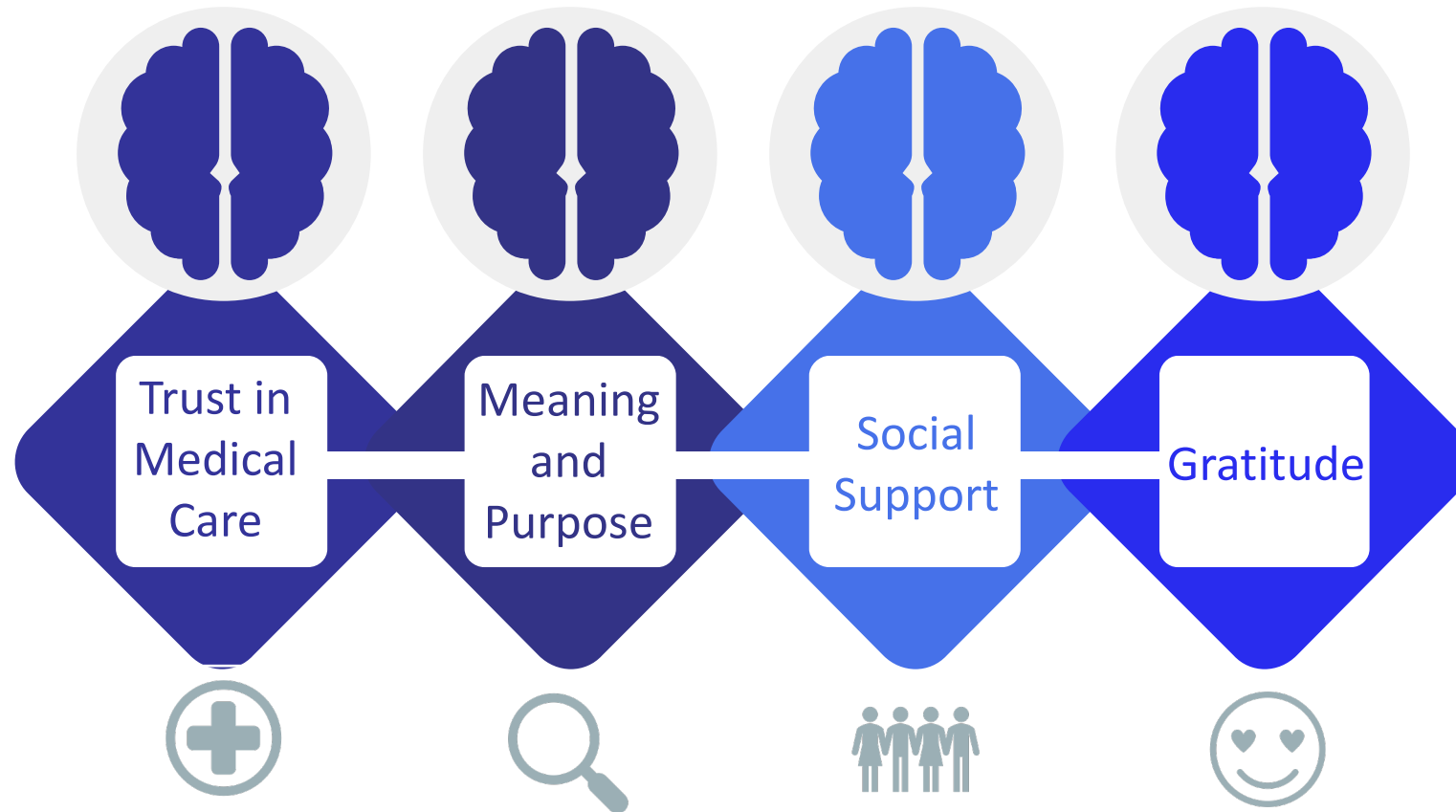
- A majority of the research focuses on illness, patient stress, and patient care <sup>2</sup>
- What about the factors that allow cancer patients to thrive or experience well-being despite their diagnosis?
- Less commonly studied in the context of disease and illness.<sup>3</sup>



The background features a repeating pattern of interlocking diamond shapes. The central diamond is white and contains the text. The surrounding diamonds are in various shades of blue, including light blue, medium blue, and dark blue, creating a layered, geometric effect.

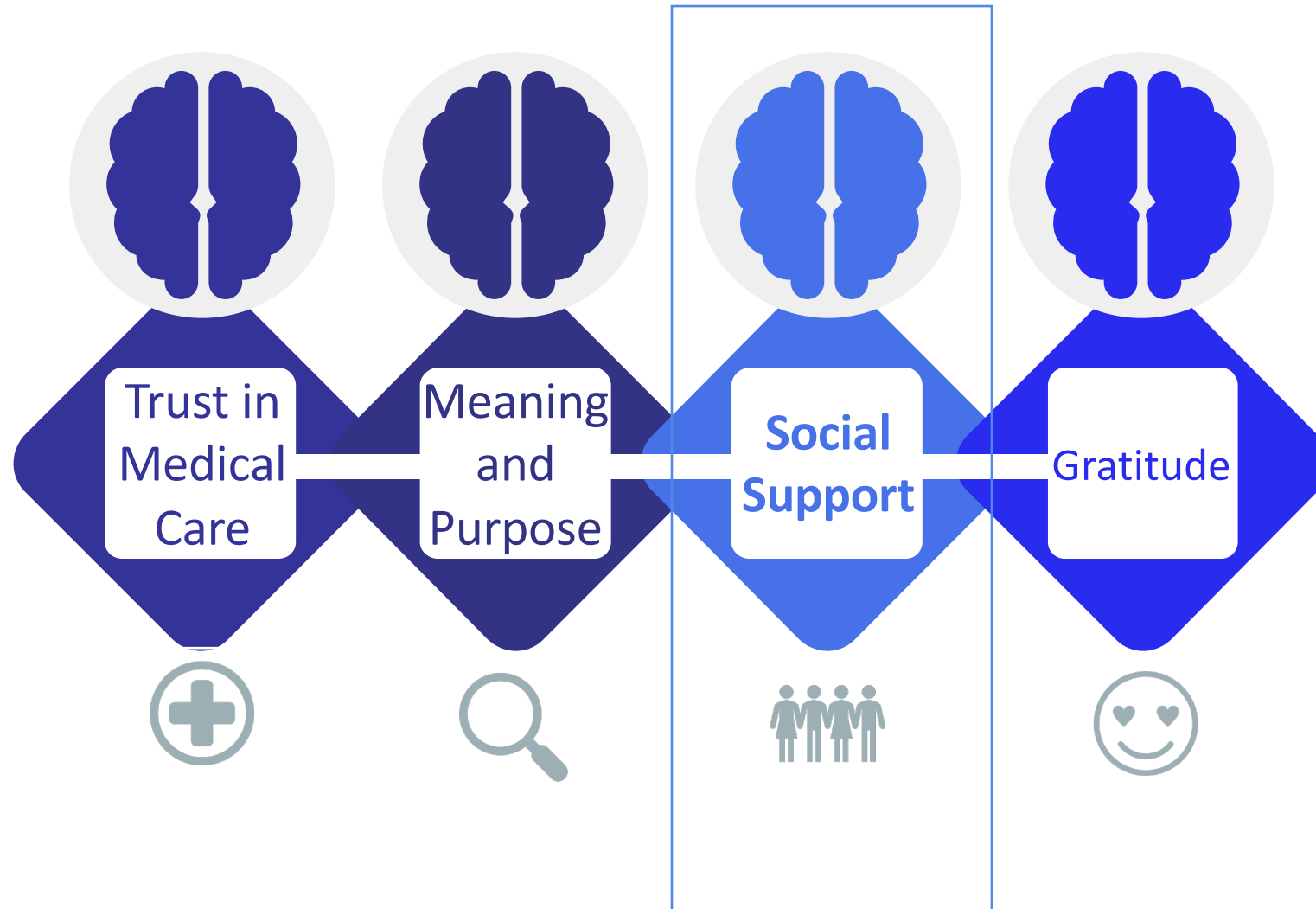
# Results

# Themes



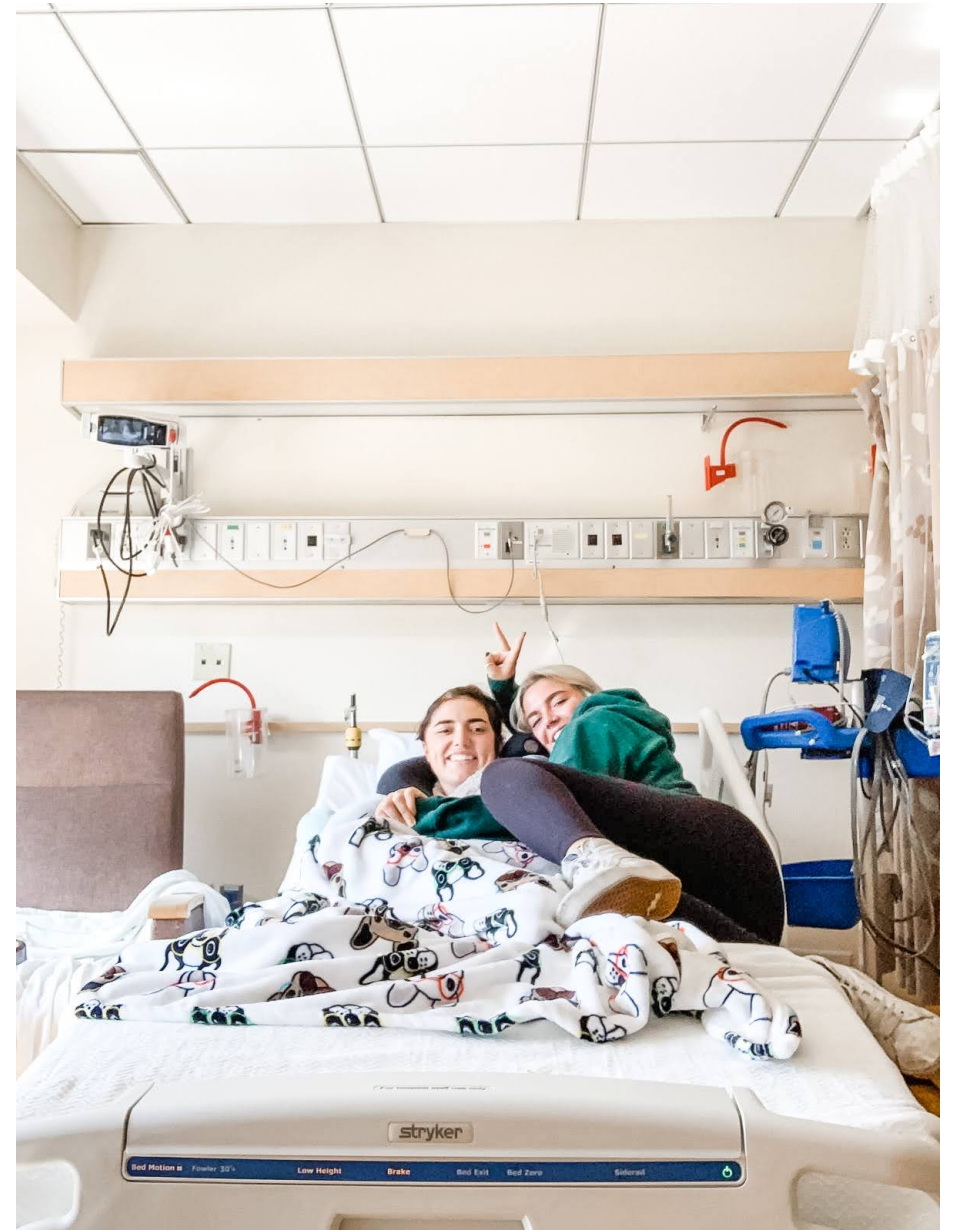


# Themes



# UTILIZING SOCIAL SUPPORT

---



**4:04**

People start to  
Look at you differently  
when they realize how fragile  
your life might be

They don't want to call  
because they don't want  
to overwhelm you...  
They mostly don't know what to do

I called my friend from the ER  
and she has called me  
    *every*  
    *day*  
    *since*

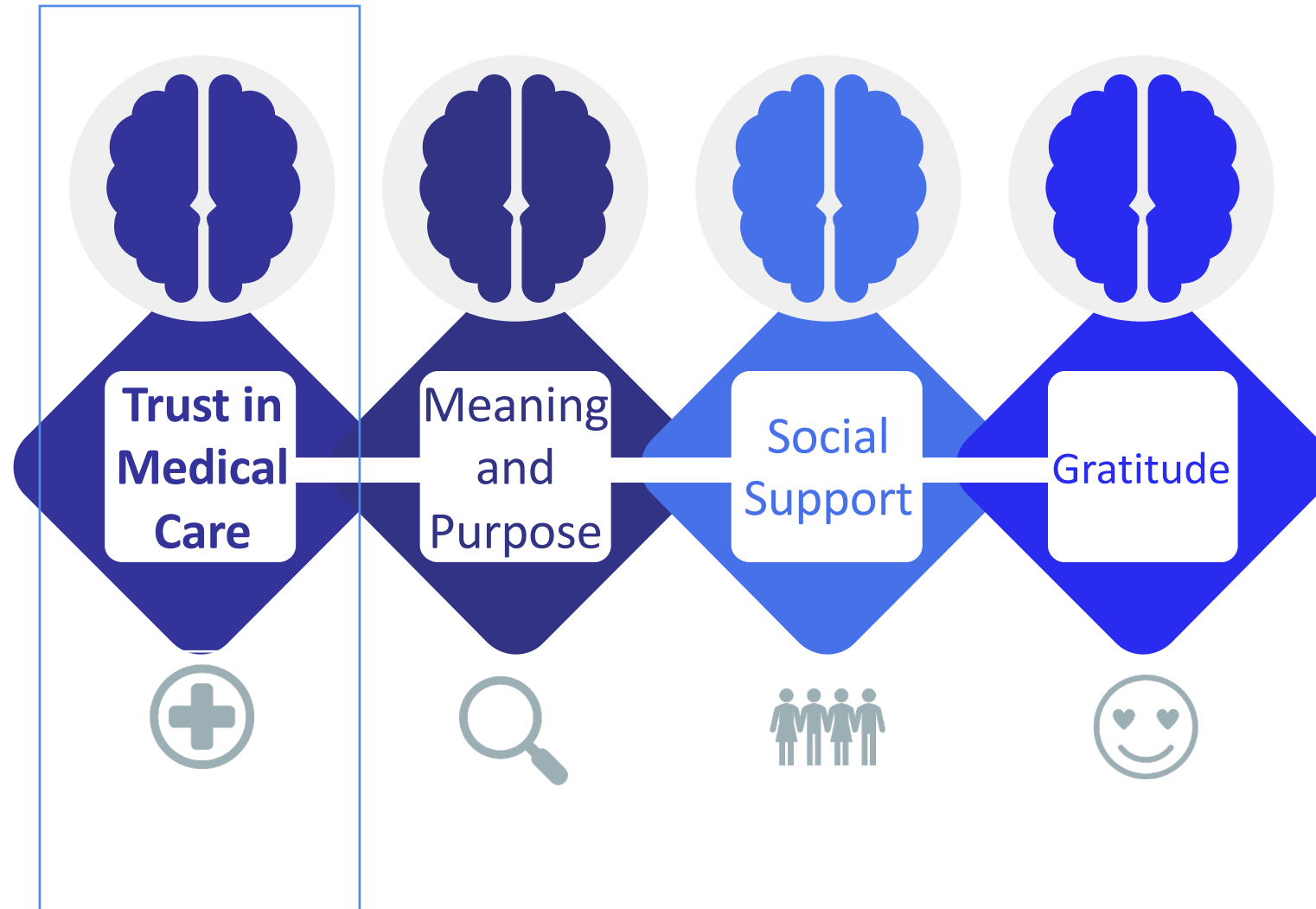
At the exact same time—  
at 4:04pm

We laugh  
We cry  
We talk  
We dream

She might not know  
that 4:04  
saved my life

I will be there at 4:04  
For anyone that needs me

# Themes







# Trust in Medical Care

---







## **Law of Attraction**

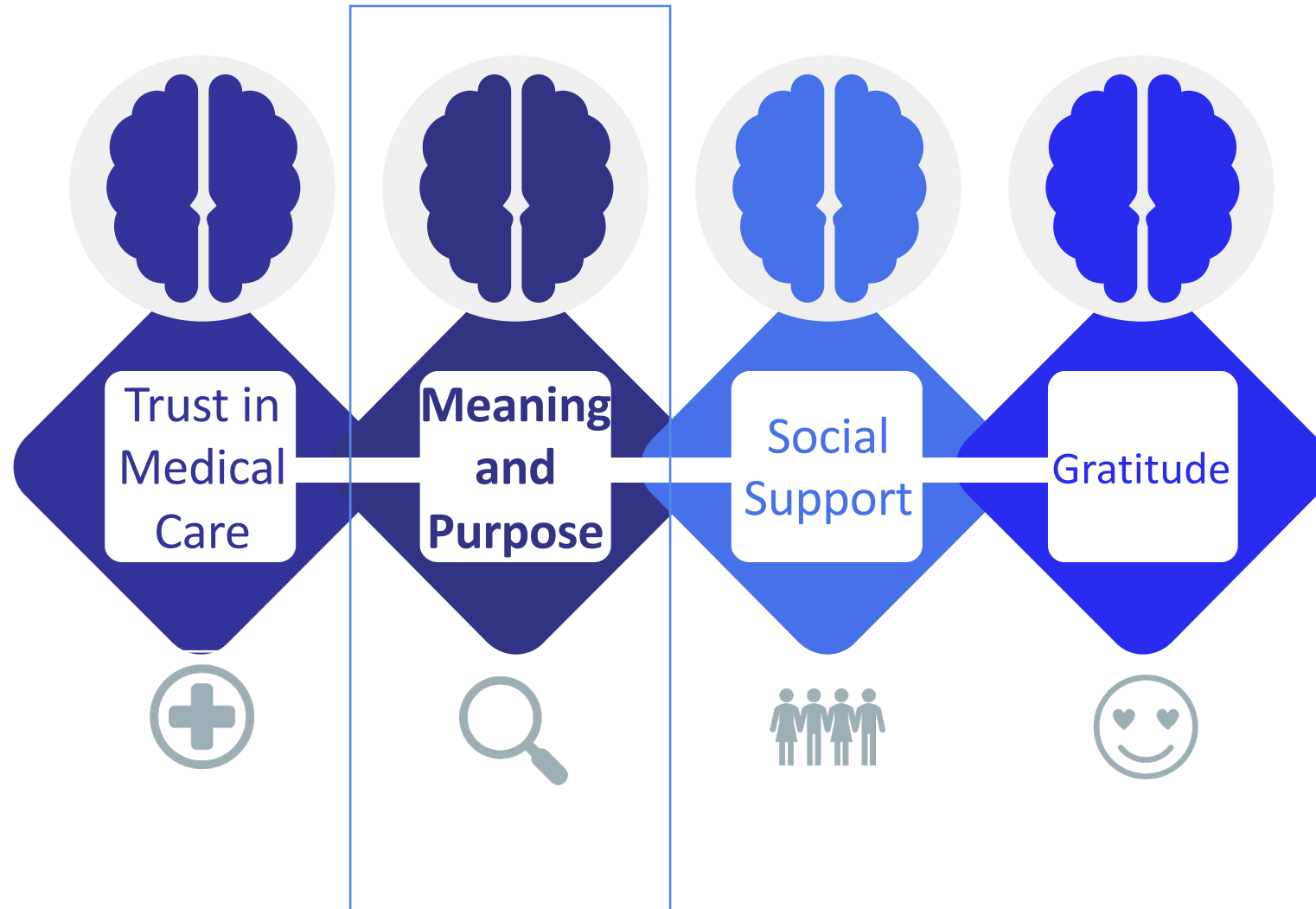
It's  
nothing  
that  
you  
did

-The doctor said-

I hope  
everyone  
can hear that

You  
did  
not  
manifest  
your  
trauma

# Themes



# Finding Meaning and Purpose

---



## **My Only Wish**

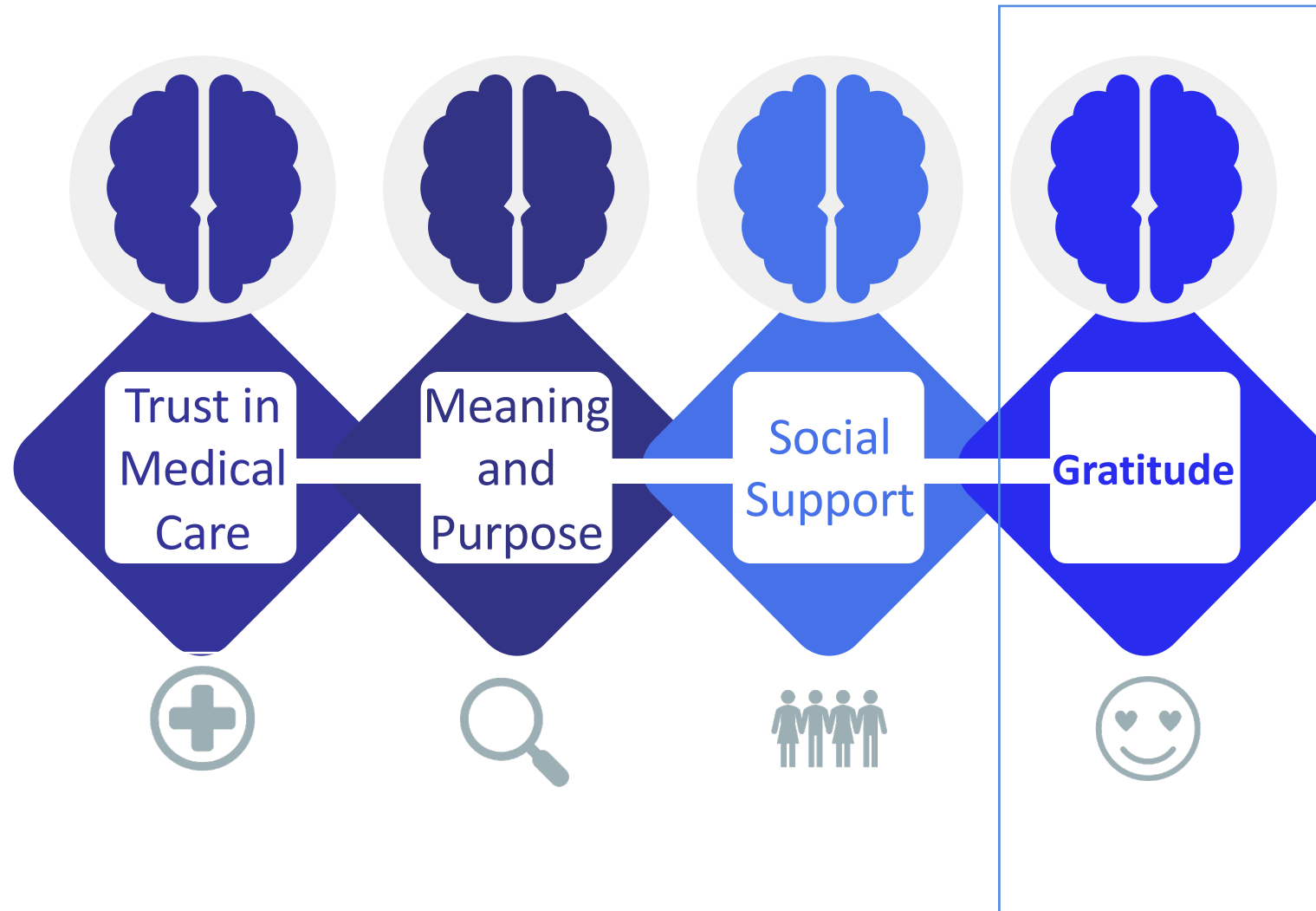
Give me  
the strength  
to carry this

Give me  
the strength  
to survive  
this

then, (please)

Give me  
the strength  
to show the others  
that  
they can  
survive it  
too

# Themes



# Self-love and Gratitude



TEDxUofM • March 2021 | 1.8M views

[Like \(54K\)](#) [Share](#) [Add](#)

## How gratitude rewires your brain

[Read transcript](#)

When a psychologist who studies well-being ends up with a brain tumor, what happens when she puts her own research into practice? Christina Costa goes beyond the "fight" narrative of cancer -- or any formidable personal journey -- to highlight the brain benefits of an empowering alternative to fostering resilience in the face of unexpected challenges: gratitude.



# I Will Keep Loving

I will keep fighting

I will keep ~~fighting~~ loving

I will keep ~~fighting~~ living

I will keep ~~fighting~~ loving

I will keep ~~fighting~~ living

I will keep ~~fighting~~ loving

I will keep ~~fighting~~ living

I will keep ~~fighting~~ loving

I will keep ~~fighting~~ living

I will keep ~~fighting~~ loving

I will keep ~~fighting~~ living

I will keep ~~fighting~~ loving

I will keep ~~fighting~~ living

I will keep ~~fighting~~ loving

I will keep ~~fighting~~ living

I will keep ~~fighting~~ loving

I will keep ~~fighting~~ living

I will keep ~~fighting~~ loving

I will keep ~~fighting~~ living

I will keep ~~fighting~~ loving

## Loving > Fighting

I am not  
at war  
with my body

The opposite

I love my body  
I love it no matter what  
I love it for the things  
it can do  
and can't

"You're young and healthy"  
"Your body will make  
connections again"

But what if it doesn't?

My body is  
worthy of loving

No matter  
what connections it makes  
No matter  
how long it takes me to move  
to write  
to feel  
to think

I love my body  
It did not betray me  
It was given  
different instructions  
And I will live and love  
those instructions

No more wars  
No battles  
No fighting

I will love it—  
through the good  
and the bad

-No exceptions-

# Reflecting on Themes



Patient trust has positive outcomes for both patients and physicians (Mechanic et al., 1996)



Preliminary evidence suggests people who seek meaning have higher levels of medical satisfaction (Wilson et al., 2012)



Social support predicts resilience in cancer patients (Molina et al., 2014)



Gratitude interventions amongst cancer patients showed greater use of coping strategies (Sztachńska, 2019)

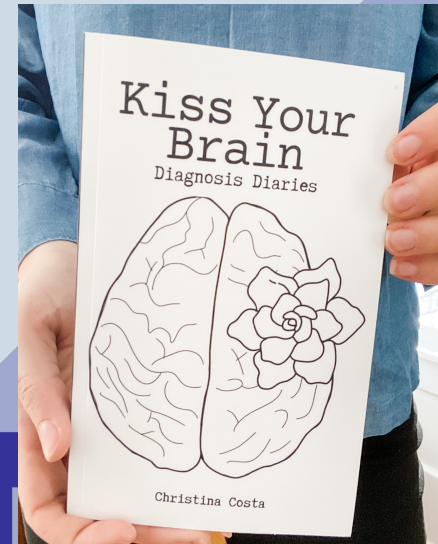


# Implications

---

- How can health care professional improve patient outcomes?
- Individual experience may help amplify *how* these themes occur e.g., patient summary write-ups
- Fostering meaning and purpose
- Gratitude interventions
- Understanding ableist messaging surrounding chronic illness, disability, and cancer

# One Last Poem





Thank you!

- Contact info:
- Email:  
naegeli@umich.edu
- IG: @ms.christinacosta