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
November
19
Migraines = Tylenol

January
20
+Blurry Vision = Tylenol + Eye doctor

March
20
+Left side numbness = Referral to neurologist for Nov

April
20
+Fainting feeling + 28 calls to Neurology Dept.

June
20
+seizures + portal message to Neurology = Neurologist appointment in early July

July
20
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\(^1\)
- Historically, most research focused on negative outcomes of adversity
- Resilience research seeks to understand how individuals thrive despite the difficulties they face

1. Davydov et al, 2010
resilience, joy, engagement
stress, anxiety, burnout
Cancer and Resilience

• A majority of the research focuses on illness, patient stress, and patient care\(^2\)
• 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.\(^3\)

Results
Themes

- Trust in Medical Care
- Meaning and Purpose
- Social Support
- Gratitude
Themes

- Trust in Medical Care
- Meaning and Purpose
- Social Support
- Gratitude
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
- Meaning and Purpose
- Social Support
- Gratitude
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
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

Trust in Medical Care
Meaning and Purpose
Social Support
Gratitude
Self-love and Gratitude

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How gratitude rewires your brain

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
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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
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.

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

But what if it doesn’t?

My body is worthy of loving

No more wars. No battles. No fighting.

I will love it—through the good and the bad.

-No exceptions-
Reflecting on Themes

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

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

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

Gratitude
Gratitude interventions amongst cancer patients showed greater use of coping strategies (Sztachańska, 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