COVID-19 AND PALLIATIVE CARE: THE GOOD, THE BAD, AND THE UGLY.

Darrell Owens, DNP, ACHPN, FAAN

Associate Medical Director – Palliative Care, University of Washington Medical Center Northwest

Clinical Associate Professor

University of Washington School of Medicine

DESCRIBE HOW YOU THINK OTHERS SEE YOU IN TWO WORDS

WHO (PRE-COVID, 2/2020)

One Palliative Care Provider (aligned with hospital medicine service)

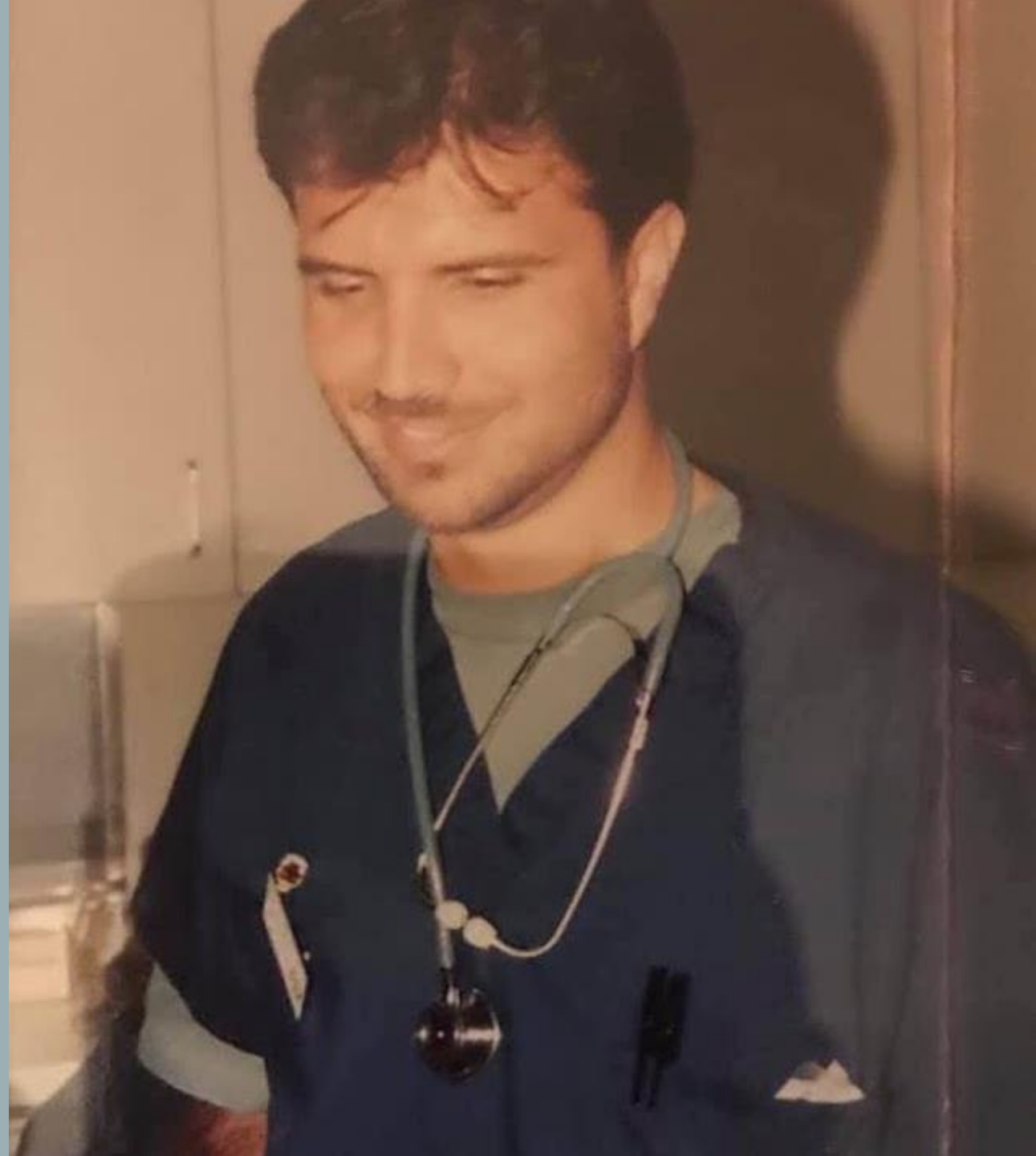
Veteran

29 years of palliative care experience

17 years in the UW Health System

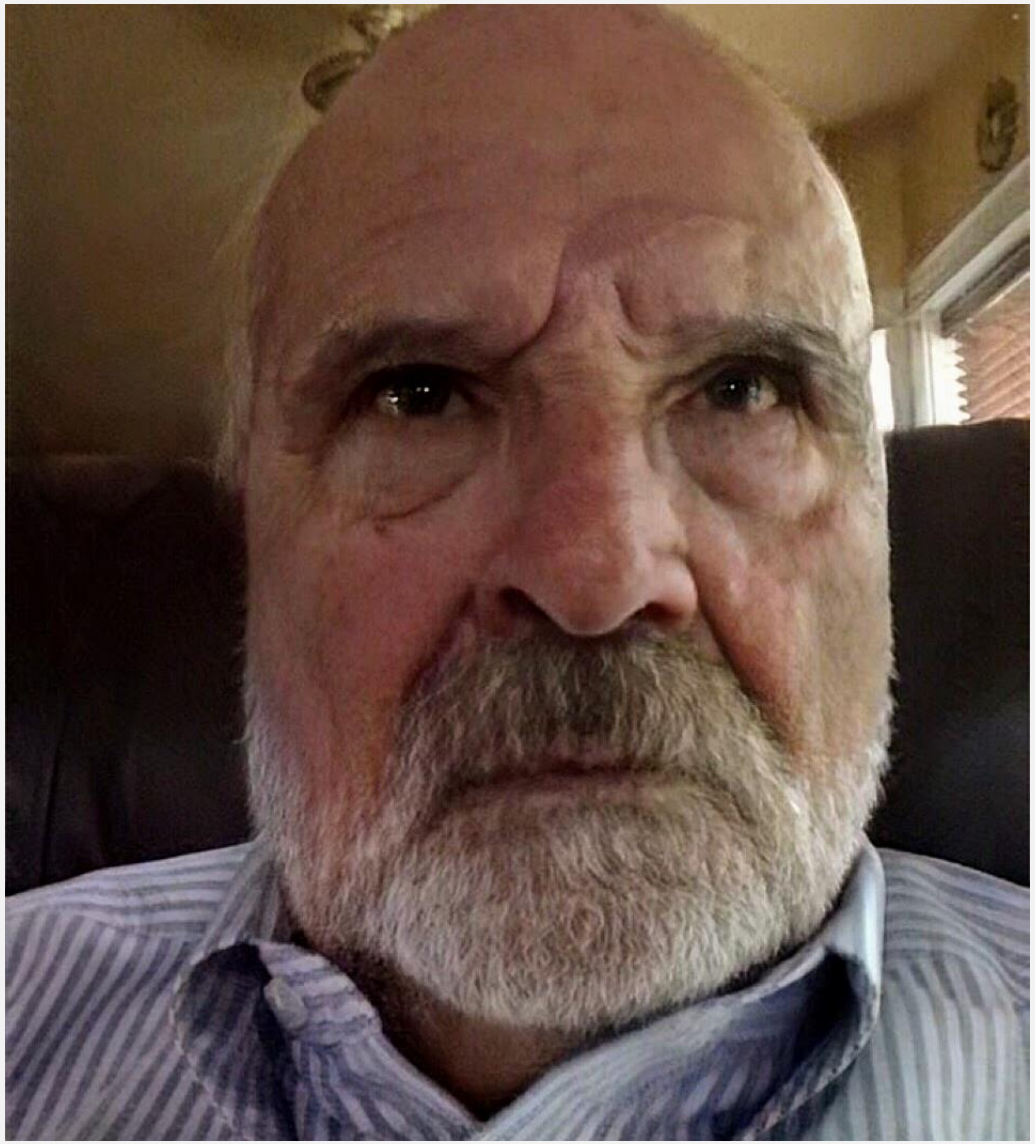
Married

One son, junior in HS



WHO: MAY 2020

- Still one palliative care provider
- > 60 consecutive days
- > 100 patients seen in ED
- > 50 death certificates
- All older adult deaths on Comfort Care



WHERE

- University of Washington Medical Center, Northwest Campus (as of January 1, 2020)
- 250-bed community hospital of the University of Washington Health System
- 15-bed ICU
- Scheduled for Epic conversion April 2020
- Located in N. Seattle
- Serves a high geriatric population

WHAT

- UW Palliative Care operates differently on each of the four campuses
- Limited shared services
- Limited shared staff
- No shared budgets
- No clinical or funding relationship with the UW Cambia Center for Excellence
- Limited shared departments
  - Internal Medicine
  - Gerontology/Geriatric Medicine
  - Family Medicine

UW NORTHWEST PALLIATIVE CARE (PRE-COVID)

- Downsized in 2017
- Predominately Inpatient Services
- One Provider
- Consulting and Primary Service
- Admits and manages all hospice GIP

HOW

- February 2020, met with hospital leadership to discuss and develop strategies for those most at risk
- Established an ED screening process based on available evidence
  - Just in time – Goals of Care
- Established a partnership with EM faculty
- Established process for admission and management of those admitted for comfort care/symptom management only
- Launched an educational campaign

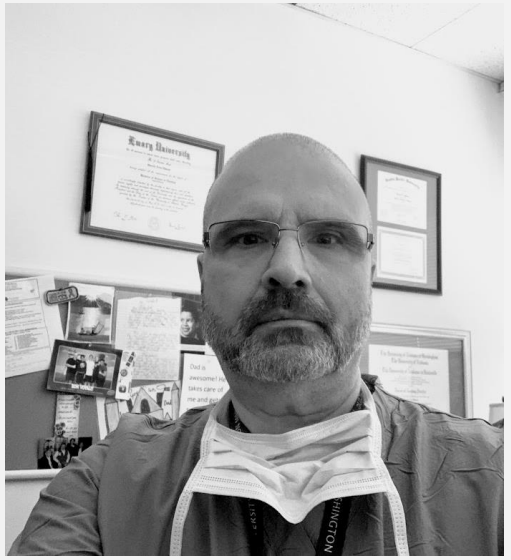
READY, SET, GO, STRUGGLE

- Not all providers embrace the program – some colleagues made the process much more difficult than it already was
- Resistance was a futile
- Week one, an outbreak in the Geropsych Unit, over 50% of patients test positive
- Multiple, difficult conversations, the majority of which were via telephone
- Symptom management challenges for those in COVID isolation – learn as you go
- Patients, families, and staff are anxious, but in general, very reasonable given the level of crisis and uncertainty

MAKING IT WORK

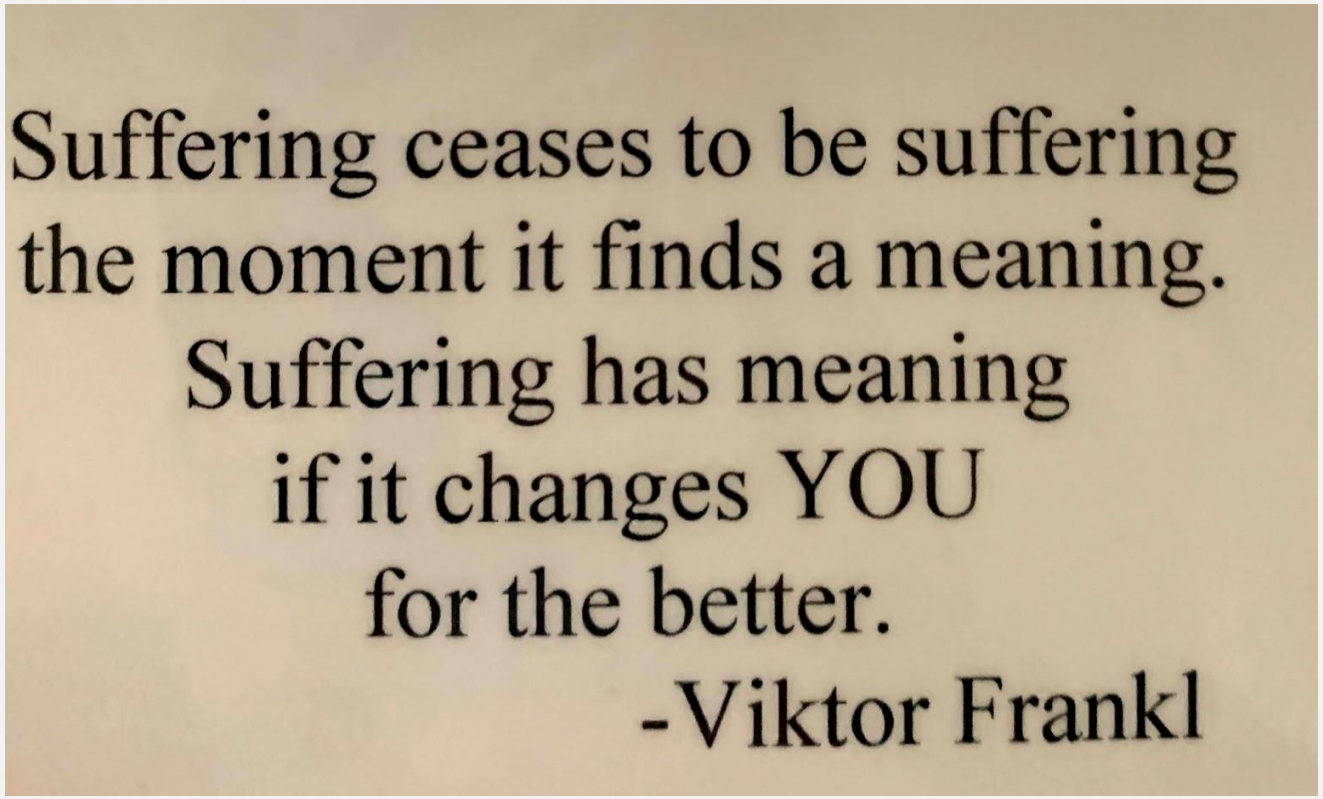
- Approximately 30 days into surge one, a COVID unit was created
- Collaboration within the hospital was high
- Tolerance to uncertainty and constantly changing landscape and procedures was high
- Physically exhausted and energized simultaneously
- Highest number of deaths in one day = 5
- No palliative care help from other UW Campuses – WHY?
- Majority of palliative providers within the system stayed home – WHY?
- No other UW palliative care services collaborated with their ED – WHY?
- Media coverage helped spread the word about what palliative care could and should be doing, e.g., NPR Morning Edition, USA Today, GeriPal
- UW palliative care publishes the article:

Fausto, J., Hirano, L., Lam, D., Mills, B., Owens, D., Perry, E., & Curtis, J. (2020). Creating a Palliative Care Inpatient Response Plan for COVID-19-The UW Medicine Experience. *Journal of Pain and Symptom Management*, *20*, 30176-7.



CHAPTER ONE ENDS

- May 2020
- 63 days of 24/7 ends
- "Given" five days off
- June 2020
- FURLOUGHED
- Hero to zero in days
- Anger/irritability begins to manifest
- Public debate of the moment mask versus no mask, business open vs. closed
- Surgery vs. no surgery, visitors vs. no visitors



CHAPTER ONE LESSONS LEARNED

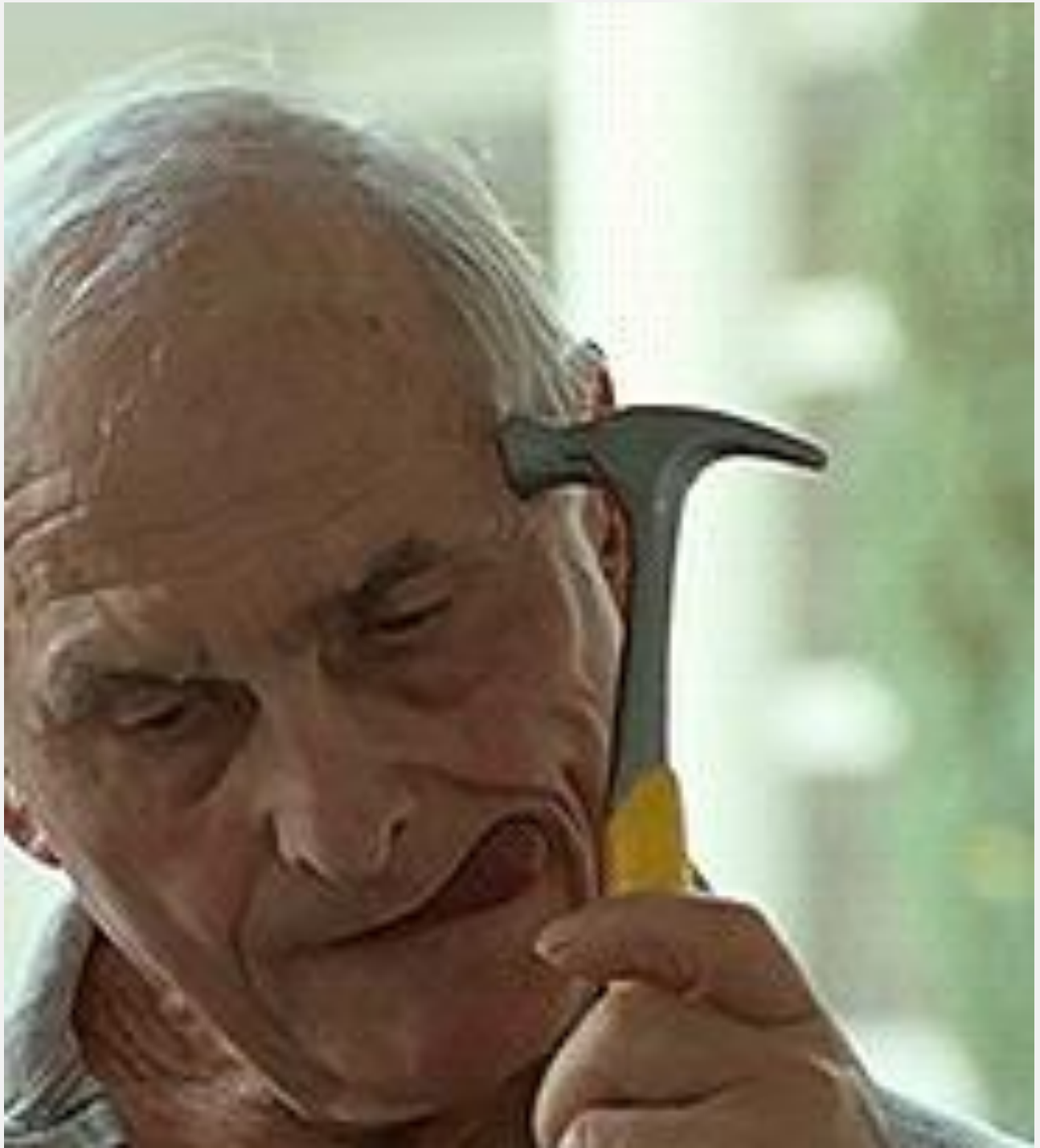
- Palliative care "can" play a critical role - it requires assertiveness
- Surgery = $$
- Attempt to resume business as usual is a failure
- Colleagues = strength and support
  - Made an honorary member of the EM faculty group
- Good work does occasionally get noticed
  - Inducted into WA State Nursing Hall of Fame
- Grief illiteracy is rampant; burnout and resilience emerge as the answers and solutions to "our" problem

CHAPTER TWO NOVEMBER 2020

- Surge #2, Deja Vue
- 24/7 ED/PC screening begins again
- Older adults are infected and die because others decline mask wearing
- Healthcare workers as heroes gone
- Anger done poorly
- Message of resilience gets LOUDER
- More PC Services across the country engage in COVID work
- Surgeries paused again = more financial woes

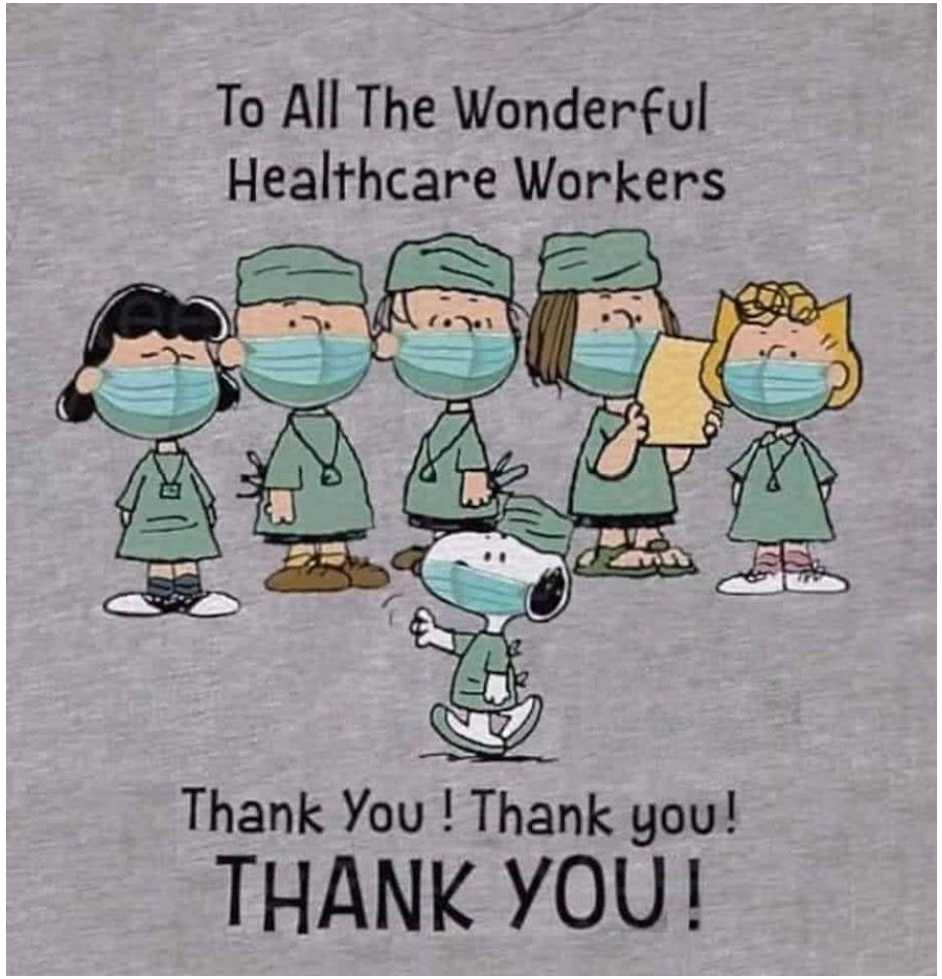
CHAPTER TWO LESSONS LEARNED

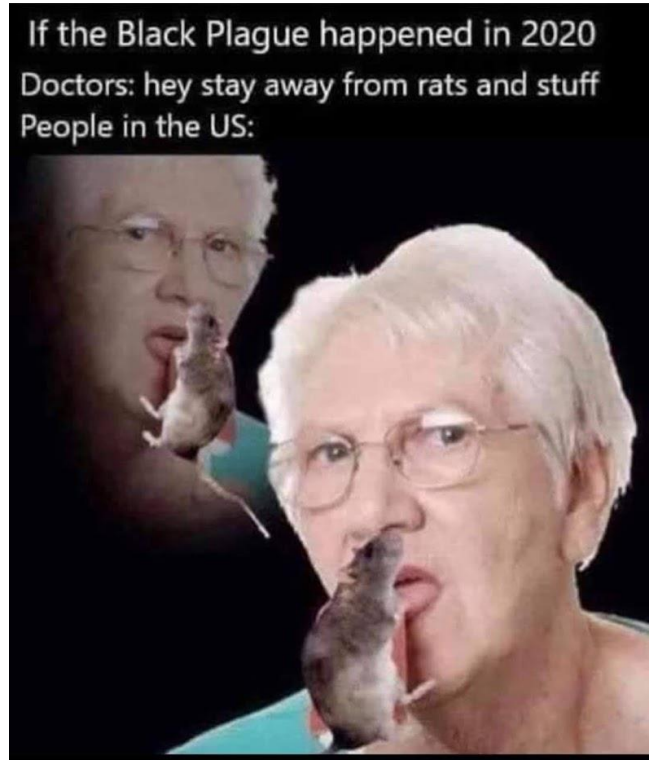
- Not many new lessons other than how to open and close a COVID unit quickly
- Public's anger increases, boundaries decrease
- Message: more resilience = fewer resignations
- Palliative care providers remain uncomfortable with anger
- Grief illiteracy continues
- Surgery still = hospital survival
- No furloughs
- Vaccines will now end this madness



CHAPTER THREE

- Vaccines available one month before surge #3
  - Mandatory for healthcare workers, increased intra-hospital conflict
  - Vaccine clinic opens, many providers and RNs volunteer
  - Seattle residents embrace vaccines; the rest of WA, not so much
  - ED screening criteria changes based on the uncertainty of how vaccinated people who become ill will do
  - Emergence of travel professionals (RN, PT, OT, Radiology Techs)
  - Institutional culture is changing


To All The Wonderful
Healthcare Workers
Thank You ! Thank you!
THANK YOU!


If the Black Plague happened in 2020
Doctors: hey stay away from rats and stuff
People in the US:

CHAPTER THREE (STILL)

- WA experiences hospital bed crisis, as does Idaho
- UW hospitals begin receiving transfers of willfully unvaccinated, critically ill patients from across Washington and Idaho representing a "different" type of patient than those traditionally served
- Apathy and anger increase in providers and staff, creating us vs. them
  - Palliative care teams uncomfortable with anger
- Continued increase in temporary staff
- Surgeries paused, AGAIN
- Cumulative losses are increasing
- Increased emphasis on resiliency and burnout –fix yourselves
- Busy ≠ cash flow

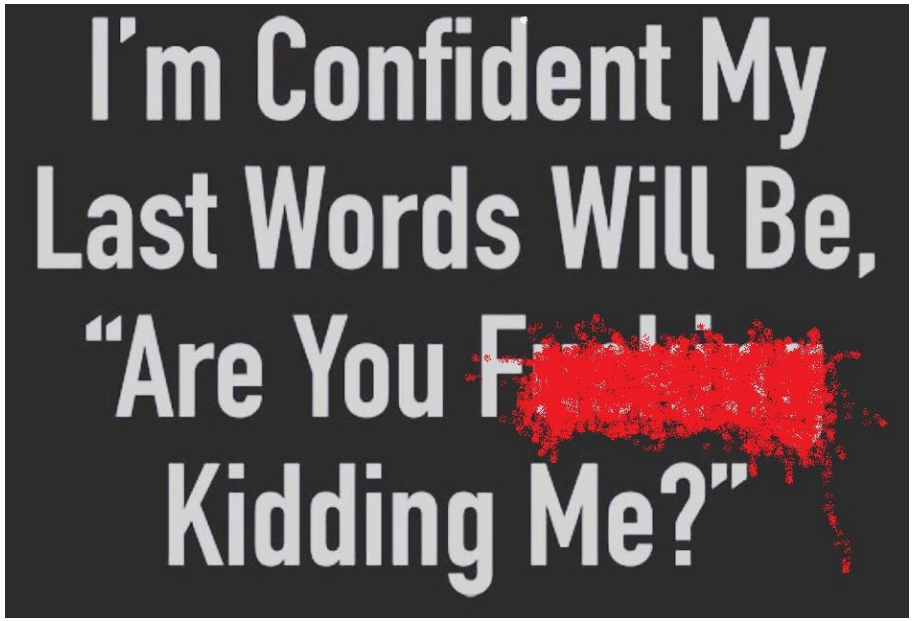
CHAPTER THREE LESSONS LEARNED

- Emphasizing provider burnout and resiliency is ineffective & can causes harm
- Providers will communicate their needs in many ways
- We don't acknowledge what we don't understand or know how to address: GRIEF
- Anger, unhappiness, and grief are everywhere
- Institutional culture has dramatically changed
- Palliative Care Services struggle with identity


Ugh.
ReactionGIF.org


RESILIENCE
Just what is needed?


Me: Be kind, you never know what someone is going through.
Also me: Nice turn-signal
face.


I'm Confident My Last Words Will Be,
"Are You
Kidding Me?"

Instead of praising people for being 'resilient', change the systems that are making them vulnerable.

Muna Abdi

GRIEF TURNS OUT TO BE A PLACE NONE OF US KNOW UNTIL WE REACH IT.

Joan Didion

power thesaurus

Synonyms for Something not right

something is wrong

something was wrong

MY PROCESS

- Step one, see prior slide
- Recognized the need to change "something"
- Engaged a therapist with experience in trauma, grief, and loss
- Engaged in EMDR
- Launched a grief and loss odyssey

Every great loss demands that we choose life again. We need to grieve to do this. The pain we have not grieved over will always stand between us and life.

Rachel Naomi Remen

MY GRIEF

- Manifestations of my grief:
  - Angry and annoyed
  - Numb
  - I Felt like I was losing it at times
  - Felt pressured to move on
  - Selfish and entitled
  - Questioned my purpose and goals
  - Anytime I mention grief, others get uncomfortable
  - My grieving style caused strain and confusion with some family, friends, and colleagues
  - It was ugly and messy

THINGS I LEARNED ABOUT GRIEF

- Grief is not a disorder, a disease, or a sign of weakness. It is an emotional, physical, and spiritual necessity, the price you pay for connection. The only intervention for grief is to grieve.
- Grief represents a continuing bond.
- Grief is the neuro psychobiological response to ANY significant loss, with elements typical and unique to each individual or situation.
- Grief is a systemic event, whether the system is an individual or a larger group of individuals thrown out of equilibrium through changes brought on by loss.
- Grief is not burnout.
- Palliative care providers know very little about grief

THINGS I LEARNED ABOUT GRIEF

- Is about a loss, a change we did not want, a lost connection
- Is as unique as your fingerprint
- Is harder to ignore than to experience
- It is like entering a room, discovering you don't want to be there, turning to leave, and realizing the doorknob is gone
- Is not a test, a gift, or a blessing; it is about a loss
- **Is not comparable**
- Is not about closure; there is no closure for grief
- Is not something you "get over" it is something you learn to live with
- People in grief are not broken and do not need to be fixed

DISENFRANCHISED GRIEF

- Defined as a loss where the survivors are not accorded a "**right to grieve**."
- Grief that people experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported.
- To speak of disenfranchisement in relation to grief is to recognize that, in various spoken and unspoken ways, social and cultural communities may deny recognition, legitimacy, or social support to the grief people experience.

DISENFRANCHISED GRIEF

- It is often the social aspect of grief that is neglected
- Every institution, culture, and society has norms that frame the way we are supposed to grieve
- These norms include expected behaviors and norms for feeling, thinking, and spiritual expression

DISENFRANCHISED GRIEF AT WORK

- In the aftermath of a loss, grieving providers and staff need varying degrees of recognition and support
- In addition to deaths, providers and staff experience a variety of losses
- Grieving providers and staff exhibit typical responses to grief
- COVID and cultural changes have left providers and staff feeling that they have lost the employer they once knew
- Most typically, grief is disenfranchised in the workplace because prevailing norms are that grief does not belong at work
- The workplace exercises significant pressure on grieving individuals to be silent about and hide their grief

DISENFRANCHISED GRIEF STUDY (OWENS, 2023)

- Hypothesis: Disenfranchised grief is under-recognized, yet present, among Advanced Practice Registered Nurses
- Surveyed advanced practice palliative care nurses in the Pacific Northwest and Northeast areas of the US, using the **Witnessing of Disenfranchised Grief Scale** (survey open December 15, 2022, through February 15, 2023
  - Higher scores = lower risk of disenfranchised grief
- Included death and non-death losses
- Recognition of losses divided into two categories of witness – social (family and friends) and leadership (administrator, director, person to whom one reported)
- Likert Scale: Strongly Agree = 5, Strongly Disagree = 1

DISENFRANCHISED GRIEF:

- Defined as a loss where the person experiencing the grief is not accorded a "right to grieve."
- Grief that people experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported.
- In various spoken and unspoken ways, social and cultural communities (including your workplace) may deny recognition, legitimacy, or social support to the grief people experience.
- The relationship is not recognized
- The loss is not acknowledged; the loss is not socially defined as significant.
- The griever is excluded.

GRIEF

- Defined as the neuropsychobiological response to ANY kind of significant loss (both death and non-death).
- Grief can also be defined as a loss or a change we did not want, or a lost connection.
- Grief can be a tangible loss: permanent loss of a life (family, friend, pet, patient) or an objective (like a home in a fire)
- Grief can be a non-tangible, non-death loss: the loss of a role, a culture (includes work culture), identity (work or personal), loss of colleagues and friends who leave institutions or geographic areas, bodily function, divorce, job demotion, loss of a person to addiction, mental illness.

WITNESS:

- Defined as someone who lets you know that your loss was real and that you had a right to grieve.
- Consider the extent to which you felt that you had a witness and answer the following questions regarding that witnessing experience. Losses described here are death and non-death related.
- For the purposes of this survey we have divided witnesses into two categories:

Witness-C represents a **colleague, co-worker, family or friend.**
Witness-A represents a **supervisor, boss, or a person with administrative responsibility.**

DISENFRANCHISED GRIEF STUDY (OWENS, 2023)

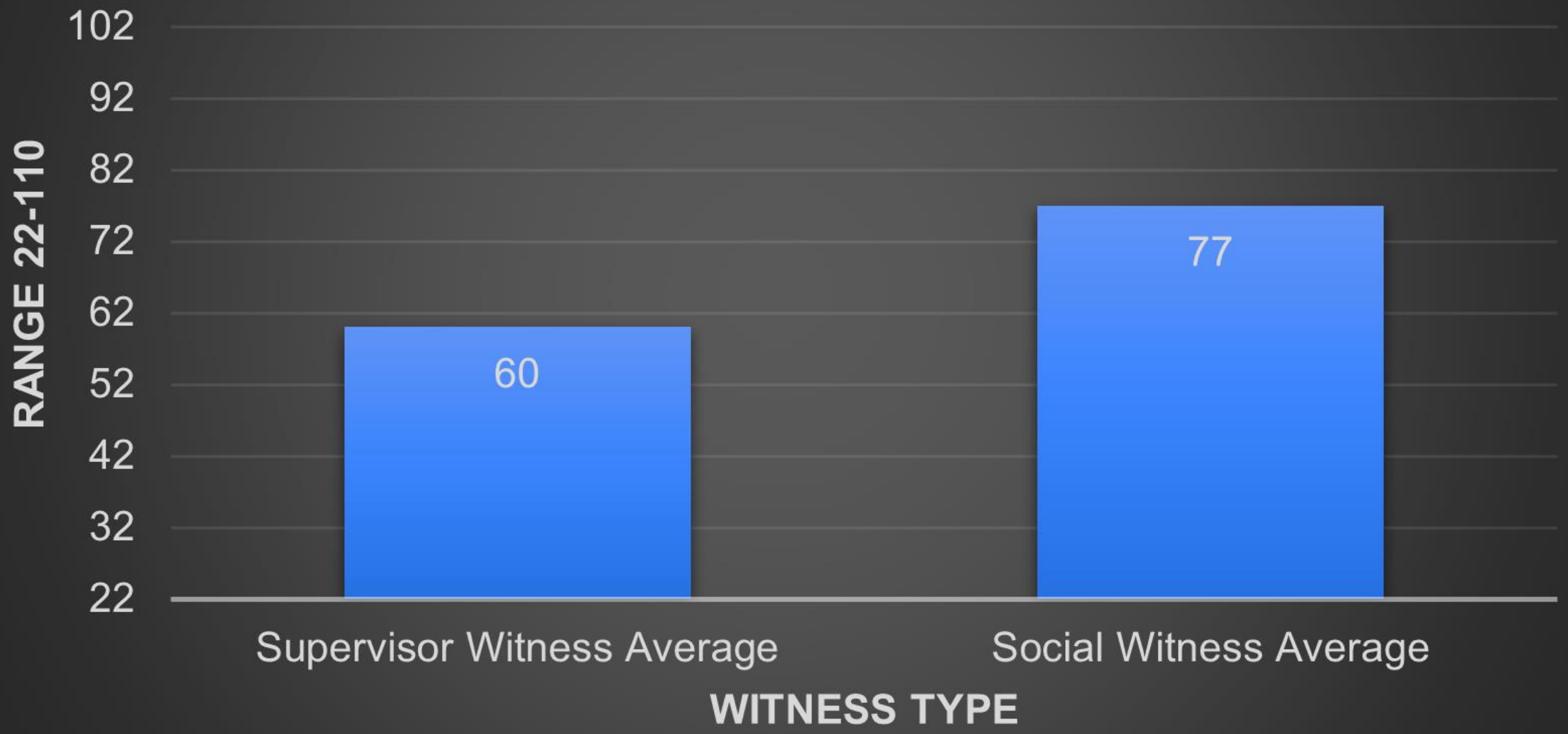
DISENFRANCHISED GRIEF STUDY (OWENS, 2023)

	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
Witness C	⬭	⬭	⬭	⬭	⬭
Witness A	⬭	⬭	⬭	⬭	⬭

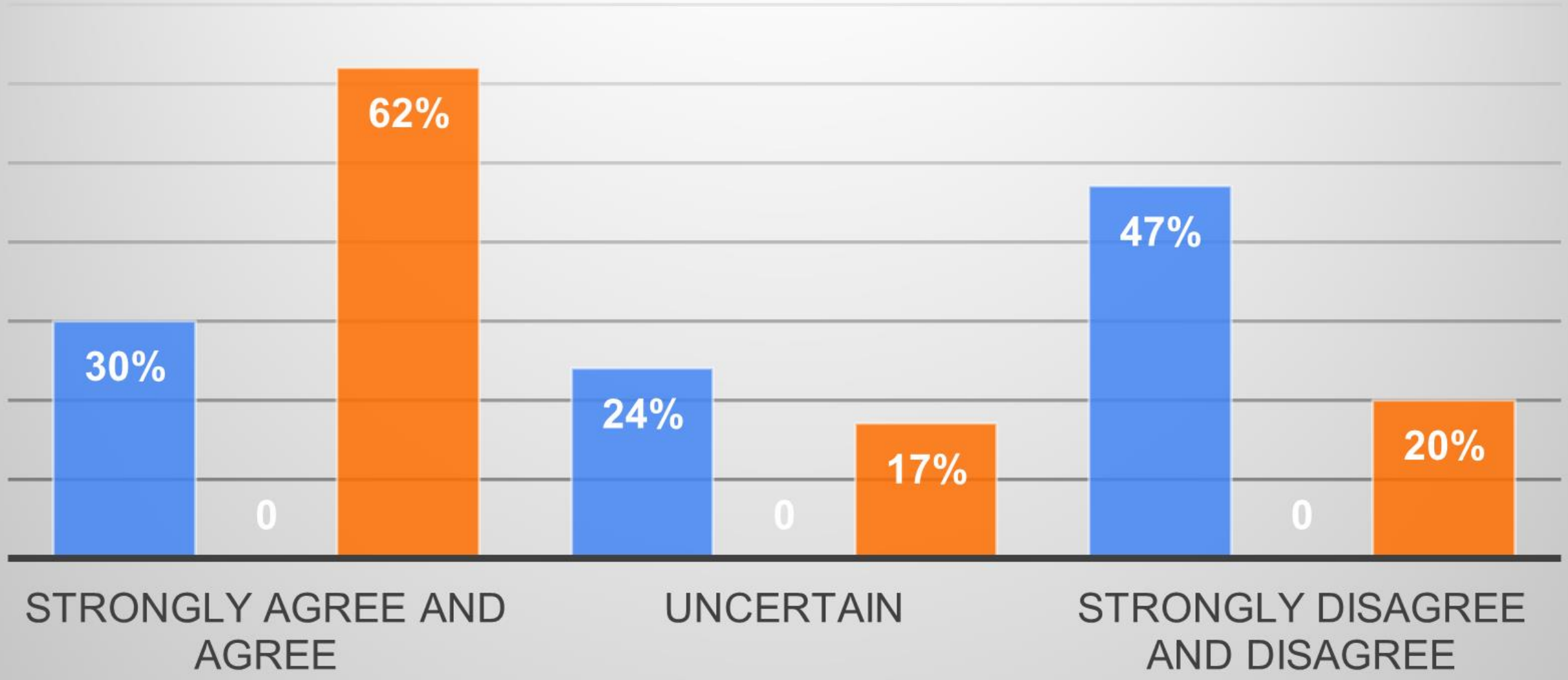
DISENFRANCHISED GRIEF STUDY (OWENS, 2023)

She/Her/Hers/Mrs.	33	62.3
He/Him/His	3	5.7
Decline to answer	17	32
Age		
21-30	2	3.8
31-40	14	26.4
41-50	18	34
51-60	13	24.5
61+	6	11.3
Total Years in Nursing		
<5	2	3.8
5-10	4	7.5
11-15	15	28.3
16-20	11	20.8
21-25	7	13.2
25+	14	26.4
Nursing Degree		
Associate	1	1.9
Bachelors	3	5.7
Masters	31	58.5
DNP/PhD	18	34
Primary License Type		
Registered Nurse	4	7.5
Nurse Practitioner	44	83
Certified Registered Nurse Anesthetist	0	0
Certified Nurse Midwife	0	0
Clinical Nurse Specialist	5	9.5
Primary Practice Type		
Administrative	1	1.9
Clinical	48	90.6
Education	4	7.5
Primary Practice Location		

Average Individual Score



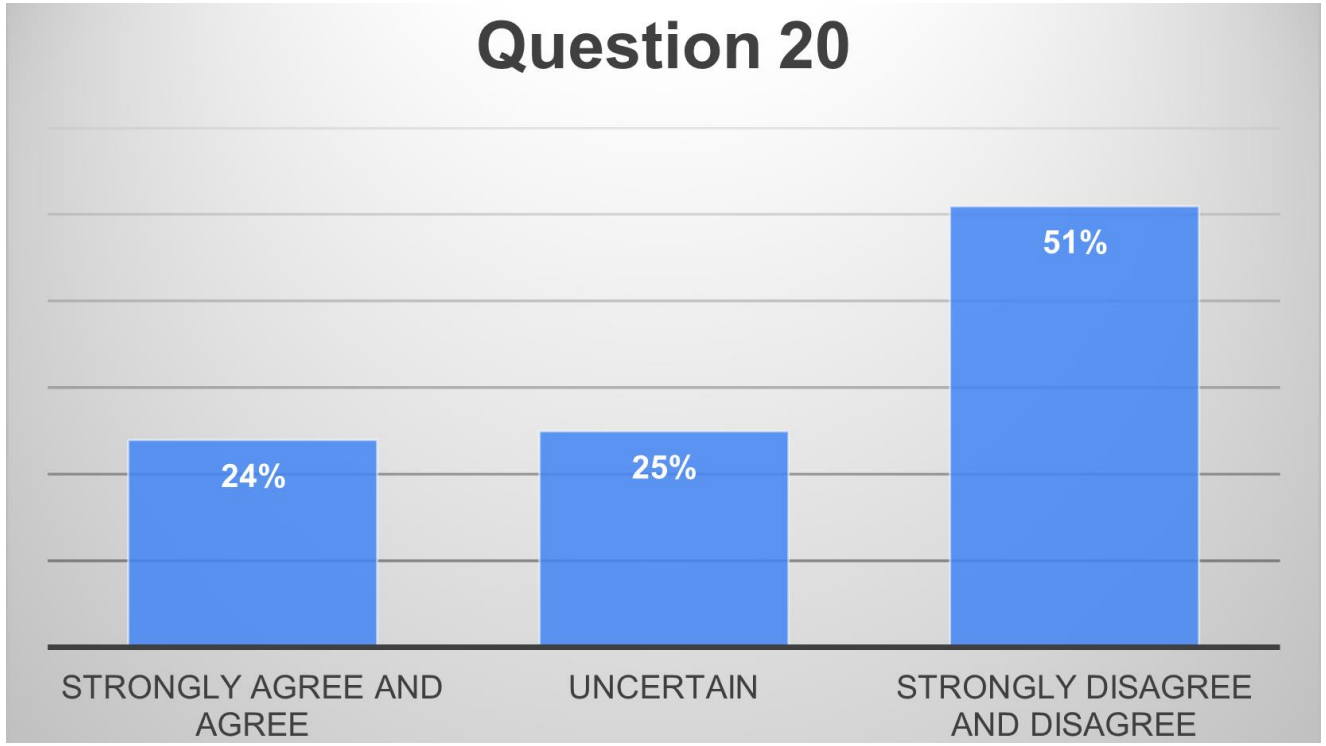
Response by Witness Type



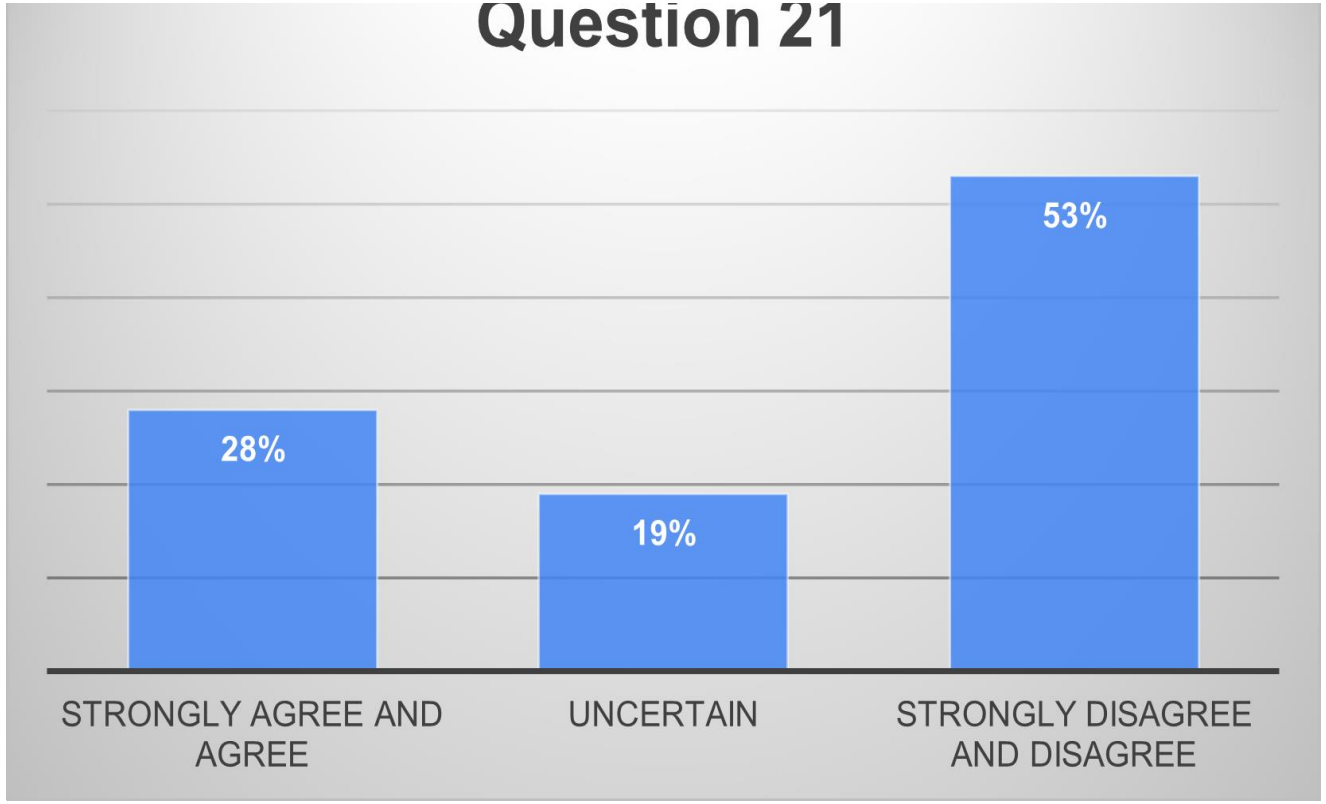
QUESTIONS WITH THE GREATEST DIFFERENCE BETWEEN SOCIAL AND SUPERVISORY SUPPORT

Question	Point Difference
5. The witness focused on my emotional pain.	43
7. I felt free to express grief in the presence of the witness 6 months after the loss.	41
18. Knowing I had a witness was a great comfort to me.	40
4. The witness talked about what I had lost.	39
12. The witness an testify to the world that I have a right to grieve the loss.	38
13. I knew the witness understood my loss just by what they said to me.	38

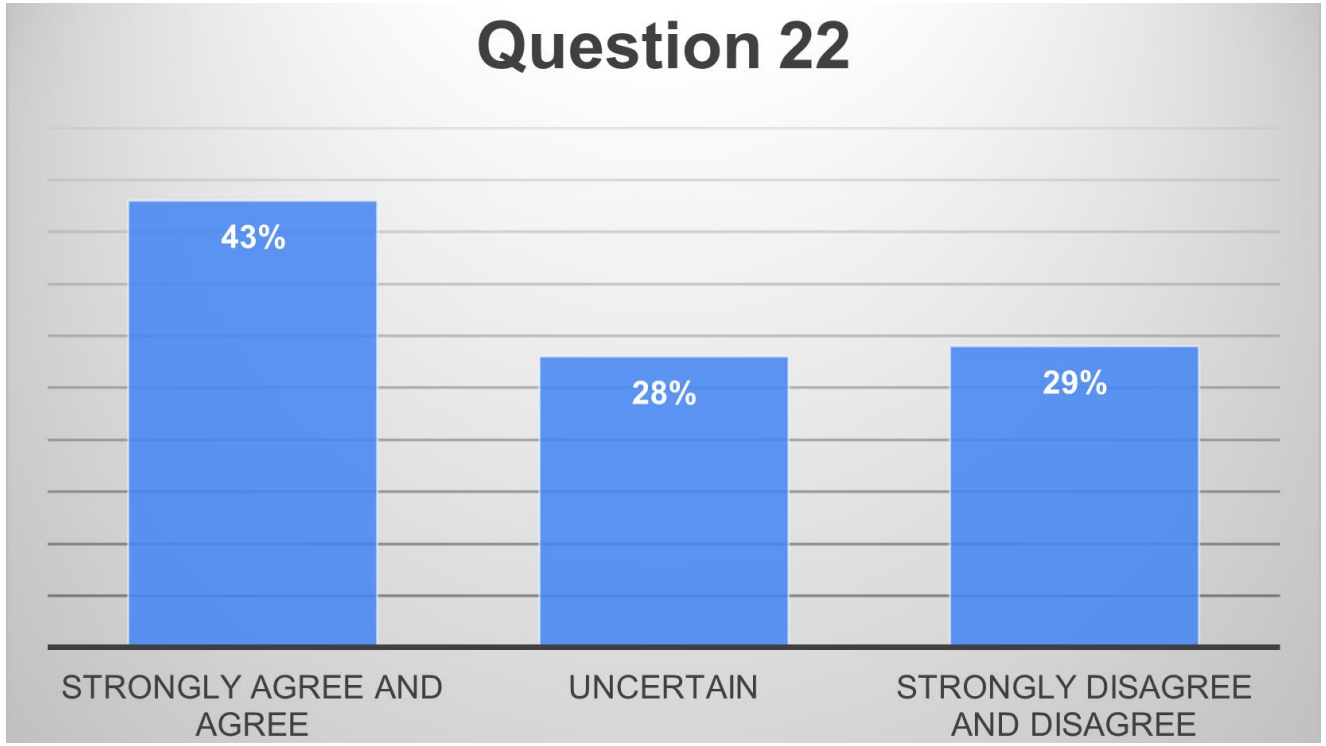
NO ONE CAN UNDERSTAND WHY I STILL FEEL THE NEED TO TALK ABOUT LOSS



NO ONE REMEMBERS MY LOSS



THE WORLD DOES NOT WANT TO HEAR THE STORY OF MY LOSS



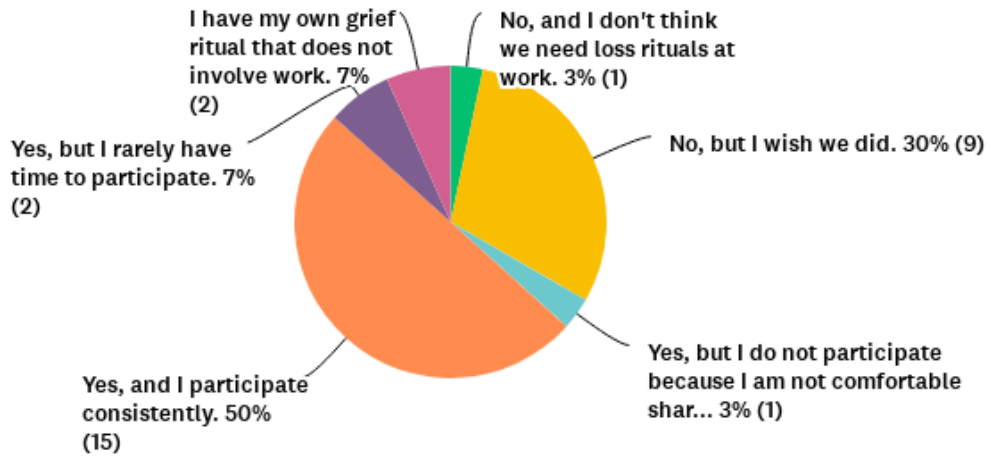
NOW WHAT?

- Disenfranchisement can be recognized as part of a broader pattern of empathic failure
- On the most individual level, a bereaved person can experience "self" empathic failure
- A central goal of clinical and self-assessment in grief is to understand where the empathic failure arises
- It is essential to remember that hesitancy in expressing grief can lead to silence.

HOW ABOUT A RITUAL?

- A highly symbolic act that confers transcendental significance and meaning on certain life events and experiences
- Rituals allow a community to come together to witness and interpret an event
- Rituals can be a powerful therapeutic tool for enfranchising disenfranchised grievers
- It is powerful to name what is happening
- It is vital that there is a name for someone's loss

Q1 Ritual plays a serious part in clinician's adjustment to death and non-death losses in the workplace. When grievers (clinicians) are deprived of ritual, the ability to process their grief may be impeded. Does your institution or workgroup provide some ritual for loss? For the purposes of this question, a ritual is anything formal that acknowledges a death or non-death loss. Check the answer most applicable to your situation.



TAKE AWAYS!

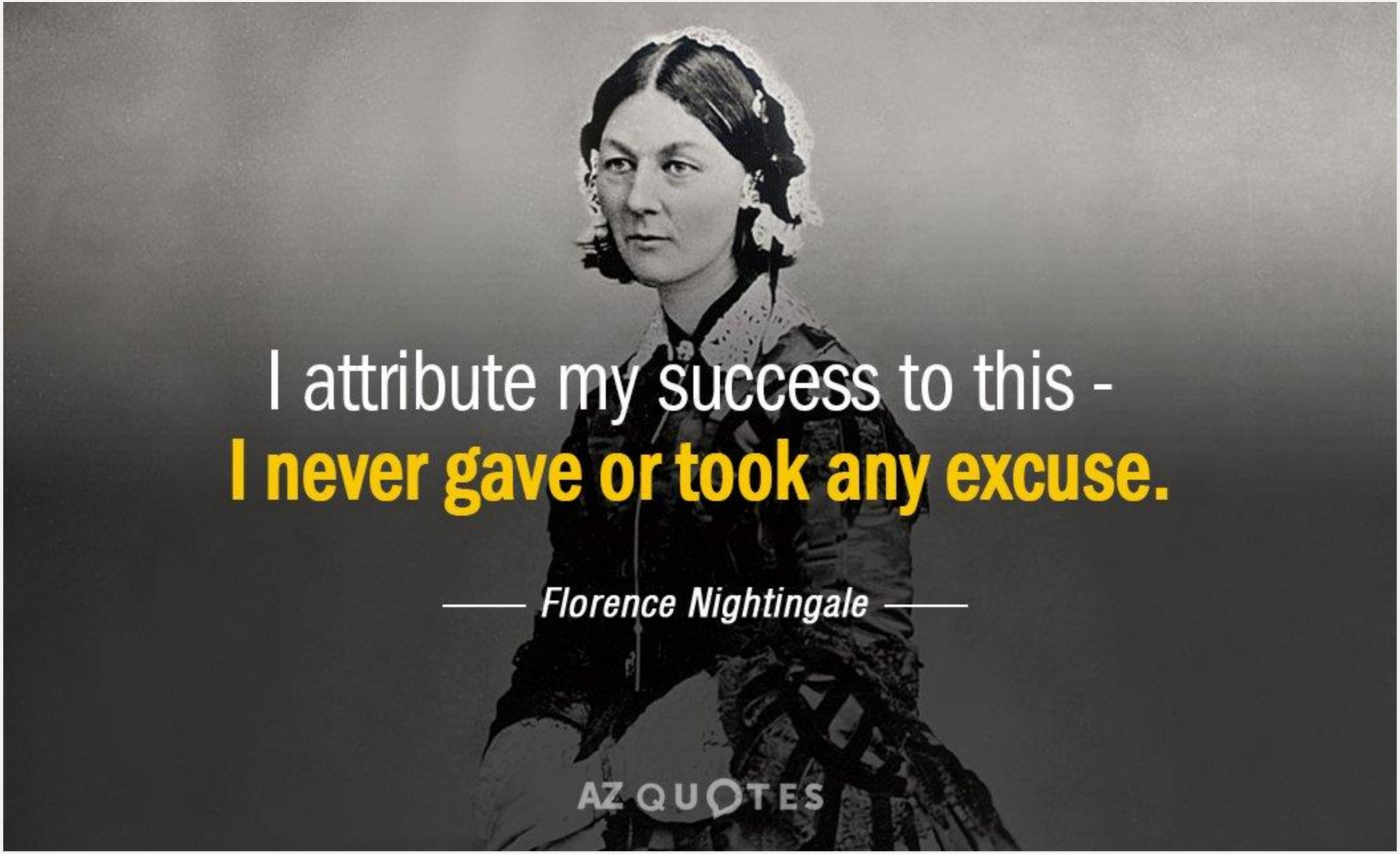
- Palliative care providers should partake in a path of reflection and introspection
- Palliative care must have a seat at the table and take an active part in disasters or crises (hint: don't wait for an invitation)
- Palliative care must evolve, which will require operation outside of comfort zones – become friends with your emotions, ALL OF THEM
- Collaborate with new partners, build relationships
- Assess what we can do differently; what works for you as a person, provider, team, institution, or specialty?
- Don't be afraid to rely on those important to you
- Stopping using the terms burnout and resilience as the cause and cure for all things "bad" in healthcare
- Recognize the role of grief and disenfranchised grief within yourself and your team
- And remember ….


NURSE
PRACTITIONERS
not your
MID-LEVEL
anything

WHAT'S NEXT FOR ME?

- Post-Traumatic Growth
  - Reduce FTE
  - Educate the next generation
    - Including self-care, grief, vicarious trauma, secondary traumatic stress
  - NP advocacy
  - Continue my work and research in the area of disenfranchised grief in healthcare
  - Continue my life-long learning via MS in Thanatology

YOUR TWO WORDS? HAVE THEY CHANGED POST-COVID?


I attribute my success to this -
I never gave or took any excuse.
Florence Nightingale
AZ QUOTES

CONTACT INFORMATION

- Darrell Owens
  - owensd@uw.edu
  - 206-650-2898 (cell)