



In the face of death:

Professionals who care for the dying

Papadatou Danai, Ph.D.

Professor of Clinical Psychology

School of Health Sciences, Nursing Dept.

National and Kapodistrian University of Athens, Greece

dpap@nurs.uoa.gr



1.1.

- Caring for the seriously ill and the dying: A relationship-centered model of care

1.2.

- Aspects of health care professionals' suffering: Effects of the pandemic

1.3.

- Health care professionals' vulnerability & resilience- "on being vulnerable enough"



*A prerequisite for asking patients to
confront mortality, I have advised professionals
first to confront their own. Weisman (1977)*

A wild force , sweeping
everything away



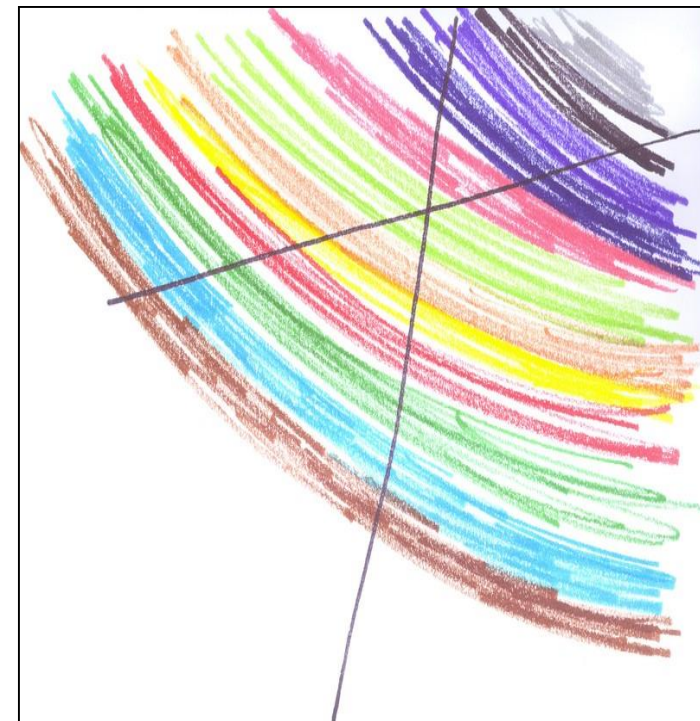
Darkness



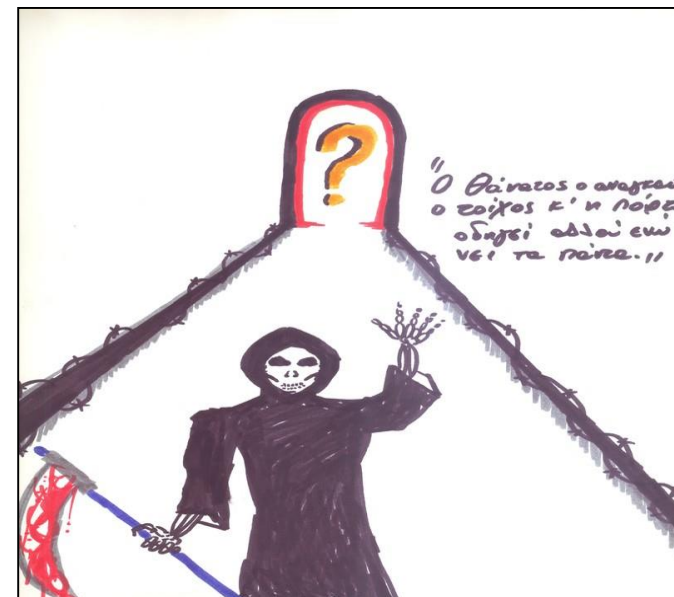
Representations of death



The monster that struggles life

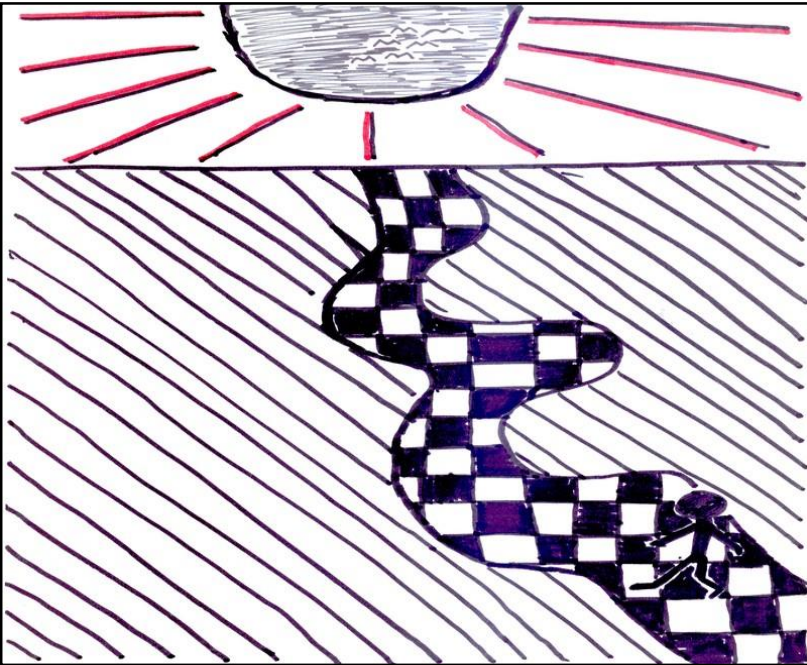


The loss of hope



The black ripper

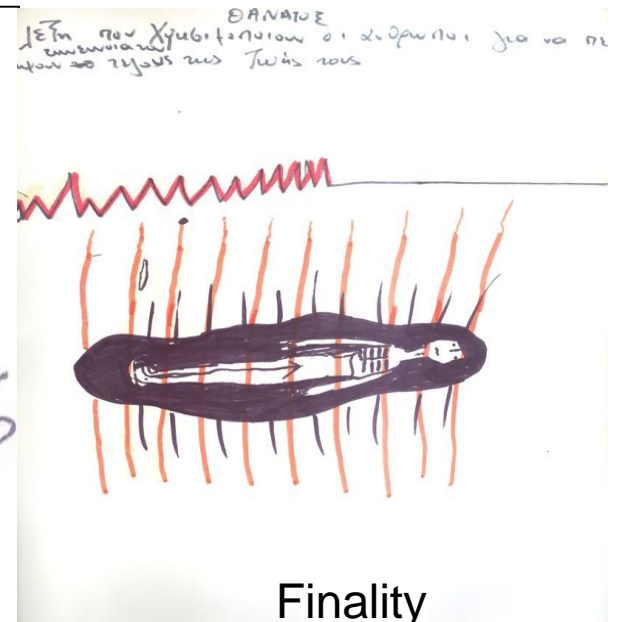
Freedom & infinite bonding



The journey



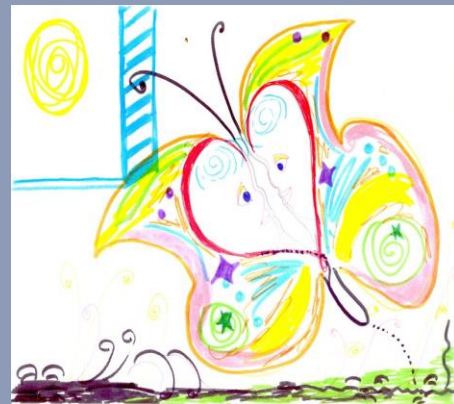
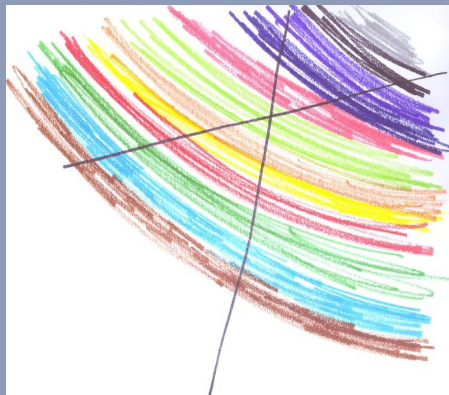
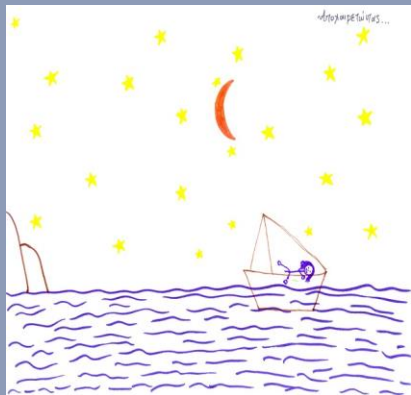
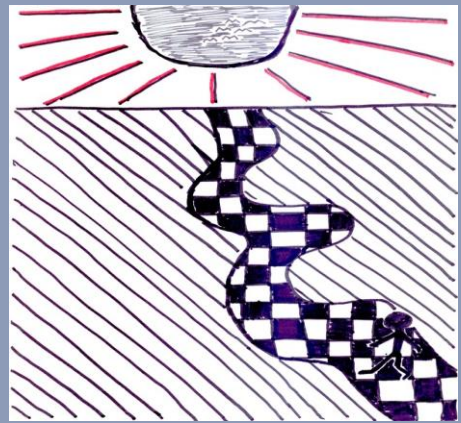
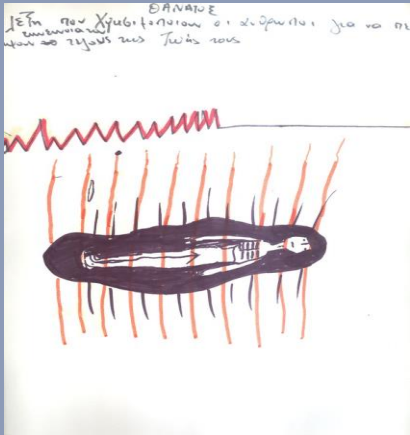
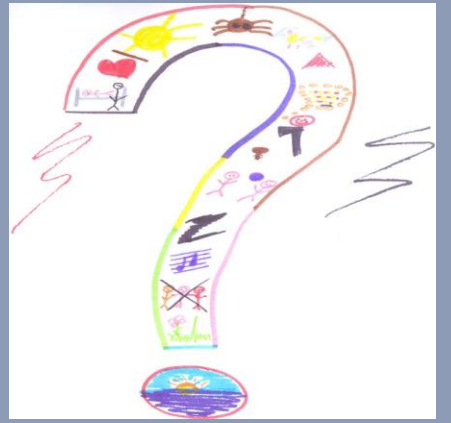
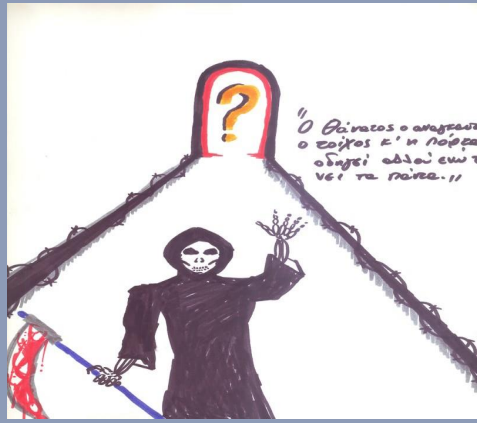
Why?



Finality

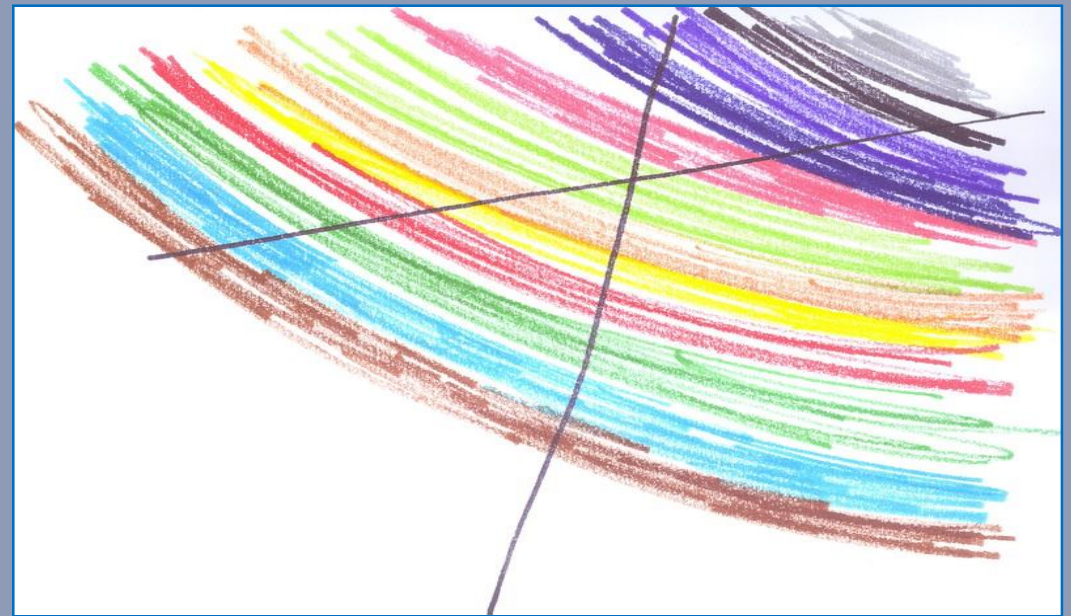


A door into the unknown





Why?

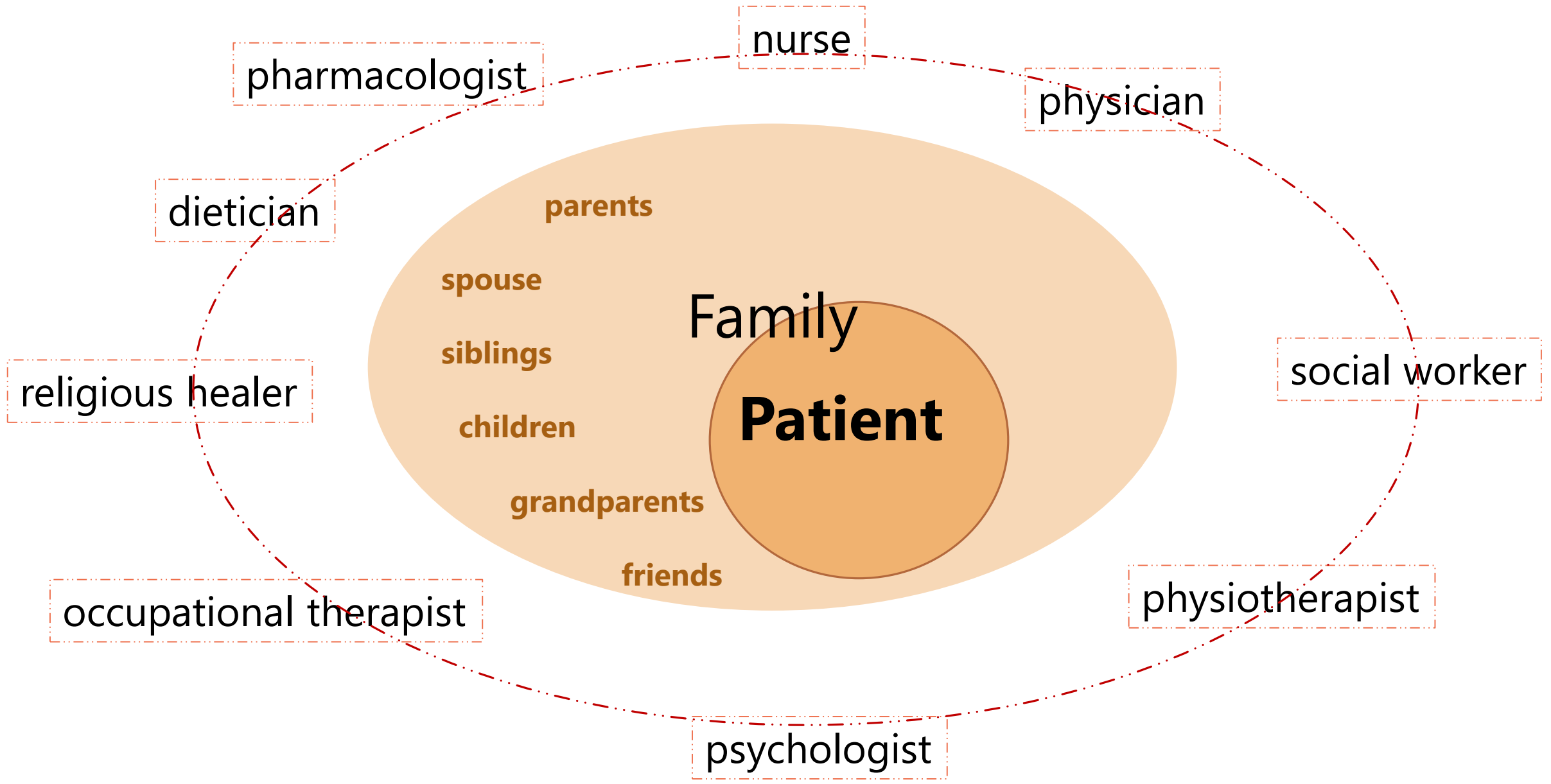


Death as the loss of hope

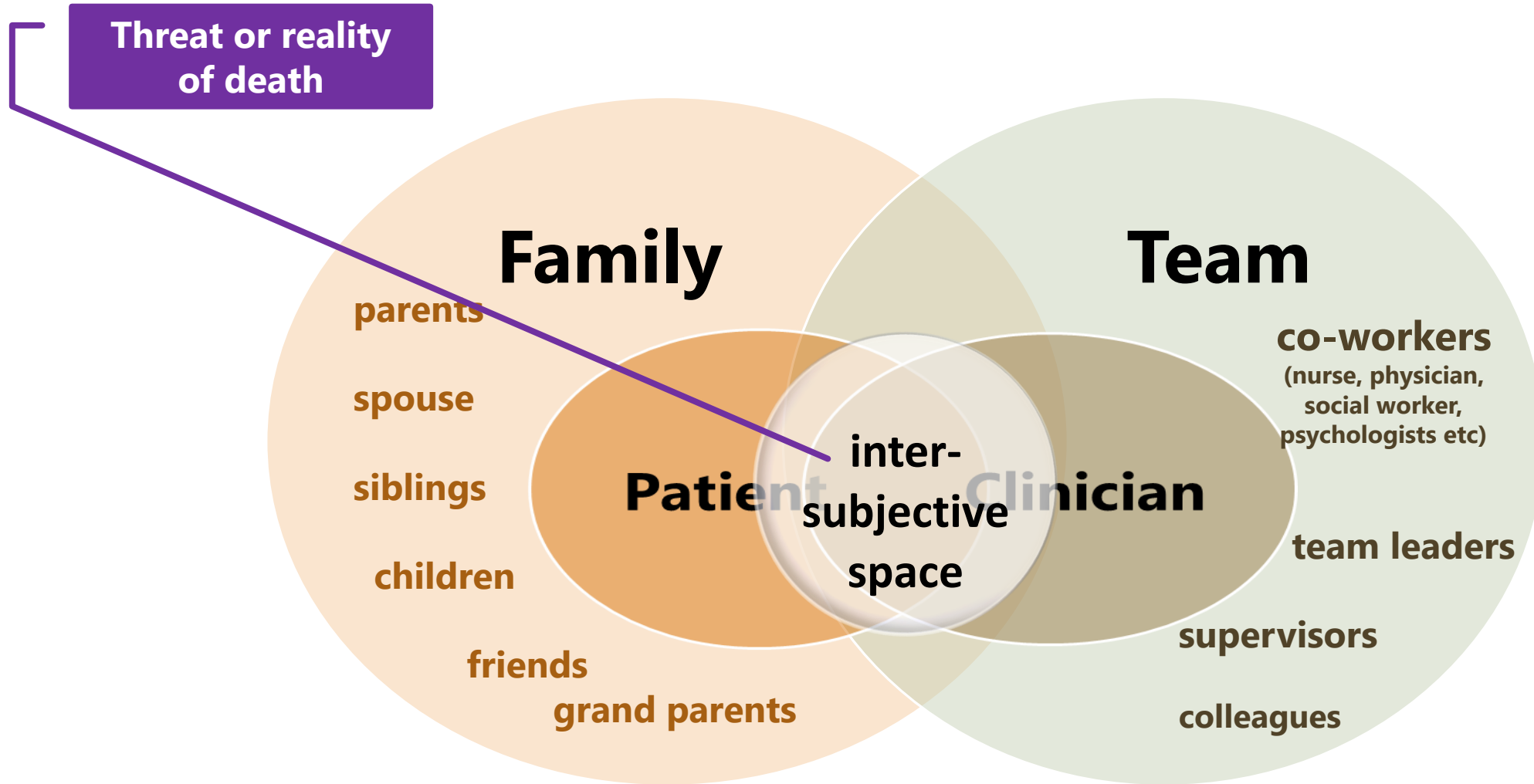


Death as a passage to new Life

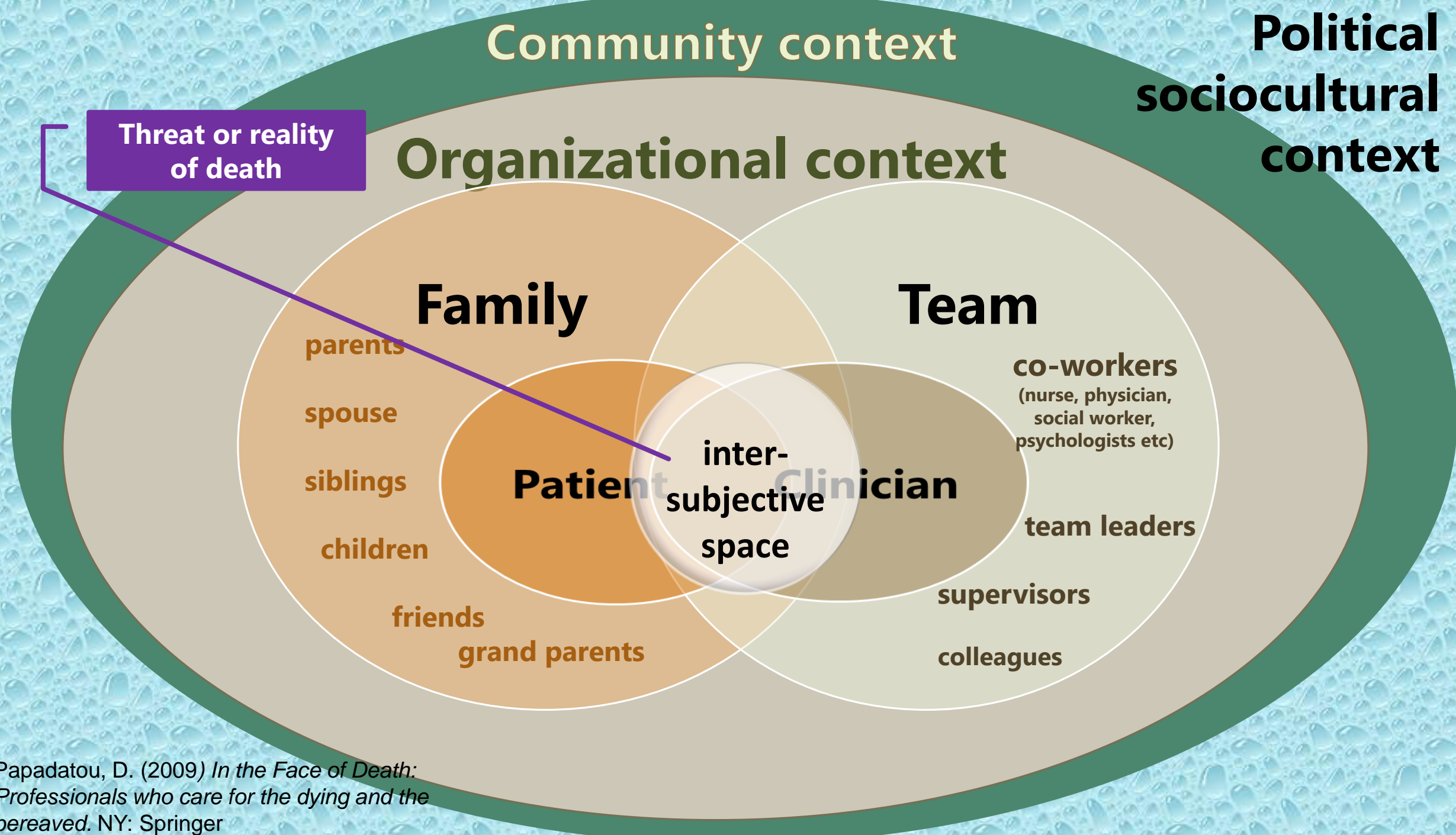
Patient & family centered model of care



Relationship-centered model of care



Papadatou, D. (2009). *In the face of death: Professionals who care for the dying and the bereaved*. NY: Springer



Papadatou, D. (2009) *In the Face of Death: Professionals who care for the dying and the bereaved*. NY: Springer



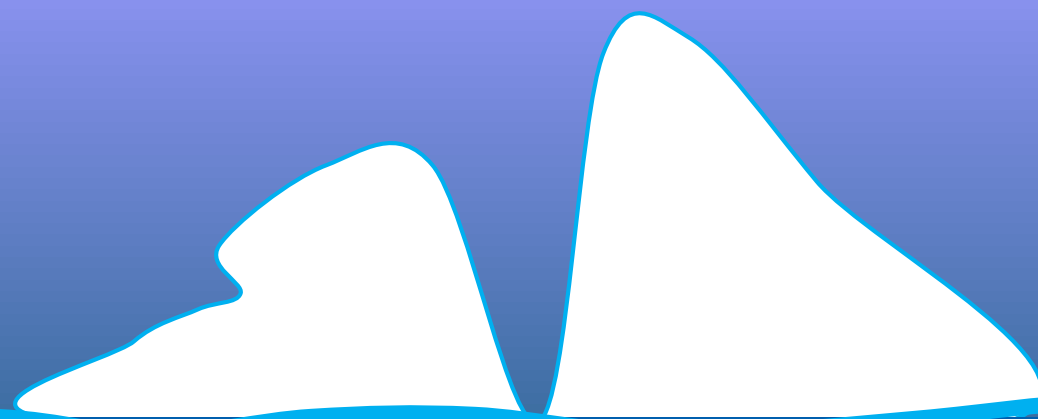
"Two birds" Escher, 1938



There are some arts,
such as the art of medicine,
which to those who use them
are *helpful*, but to those who
practice them, are *grievous*....

**"The healer sees terrible sights,
touches unpleasant things,
and the misfortunes of others
bring a **harvest of sorrows**
that are peculiar his."**

Hippocrates, Breaths I.
Loeb Classical Library, Cambridge:
Harvard University Press



Disenfranchized suffering

An iceberg floating in a blue gradient sea. The visible tip is white, while the submerged part is light blue. A vertical yellow line divides the submerged part. A yellow triangle is on the left, and a pink triangle is on the right, both pointing to the submerged part. The background is a blue gradient.

**Manifestations
of a suffering
associated with
impairment
& poor
quality of care**

**Manifestations
of a suffering
that is
unavoidable,
adaptive
and healthy**

An iceberg diagram with a blue-to-white gradient sky above the water and a dark blue-to-teal gradient ocean below. The visible tip of the iceberg is white and contains the text 'Suffering associated with impairment & poor quality of care'. The submerged part of the iceberg is much larger and contains three definitions of psychological states: 'Burnout', 'Direct or Vicarious traumatization', and 'Moral Injury'.

**Suffering
associated
with
impairment
& poor
quality of care**

Burnout

A state of physical, emotional and mental exhaustion caused by long term involvement in emotionally demanding work situations

Direct or Vicarious traumatization

PTS or PTSD as a result of direct exposure to traumatic situations

Changes of one's identity, world view, and meaning of life as result of listening to the trauma of others

Moral Injury

Very high distress that results from actions or the lack of actions which violate one's moral beliefs or ethical code

Suffering associated with impairment



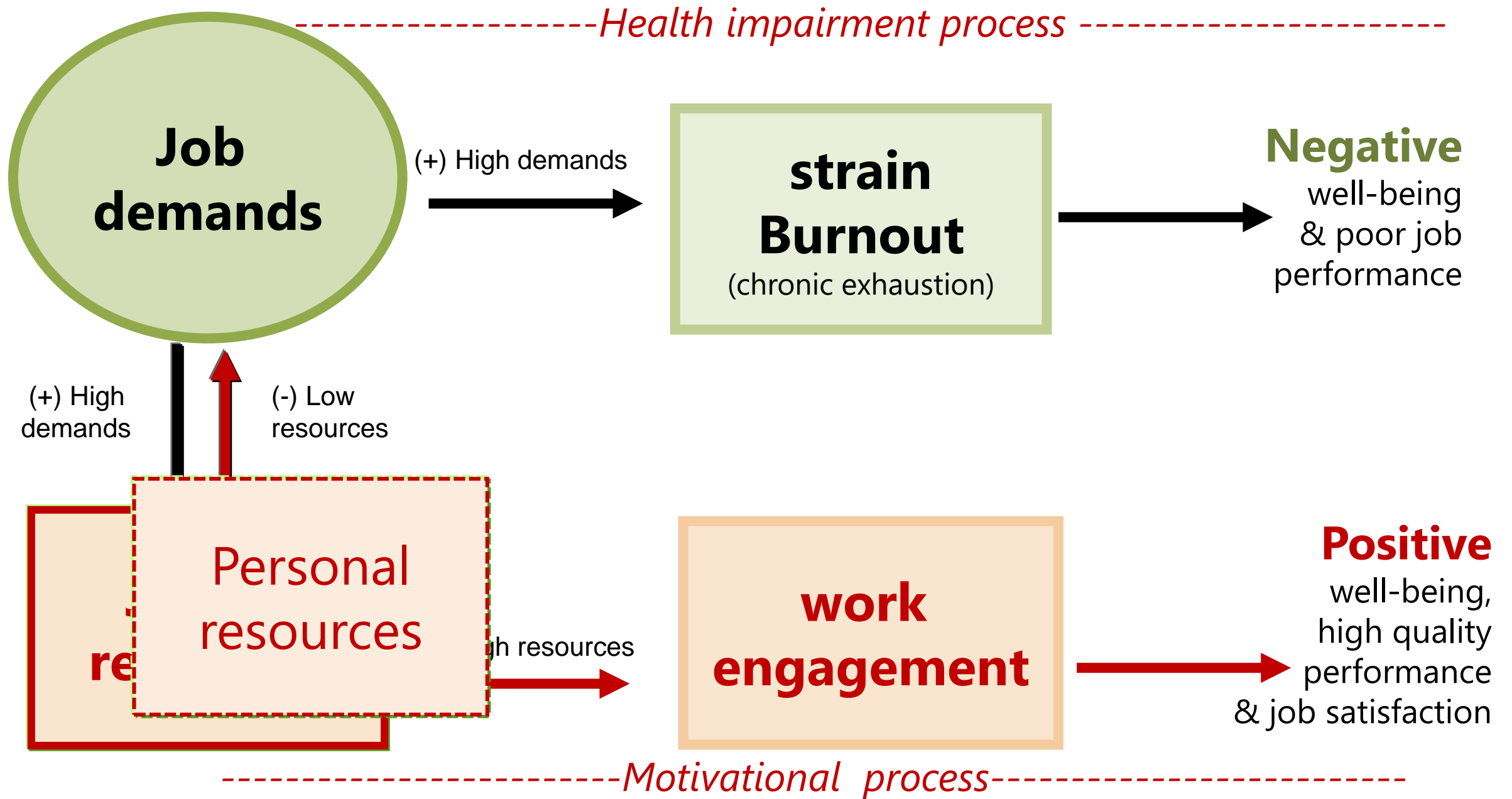
Burnout

A state of physical, emotional and mental exhaustion caused by long term involvement in emotionally demanding work situations

- **Emotional exhaustion**
- **Depersonalization**
(impersonal approach towards patients and families)
- **Reduced sense of accomplishments**

Maslach, C. (2003). *Burnout: The cost of caring*.

Leiter, M., Bakker, A., Maslach, C. (Eds.) (2014). *Burnout at work: A psychological perspective*.



Suffering associated with impairment



Traumatization

caused by direct exposure to an event that is perceived and experienced traumatically

Traumatic responses

such as PTSS, PTSD, depression, increased anxiety and sense of helplessness, hopelessness or meaninglessness, etc

Suffering associated with impairment



Vicarious traumatization

Progressive transformations
leading to major changes of one's
identity, world view,
and
meaning of life
affecting
basic needs for
safety, trust, self-esteem,
intimacy & control

Pearlman L, McCann L. (2008). *Understanding and addressing vicarious trauma*.
Headington Institute.

Suffering associated with impairment



Moral injury

Perceived actions or the lack of actions which violate one's moral or ethical code.

Development of a very negative view of

self

("I'm a terrible person")

others

("my colleagues do not care about people's lives")

institutional & governmental authorities

("they exploit, are untrustworthy, or indifferent to HCPs and their safety")

Hines S.E. et al., (2021) Trends in moral injury, distress and resilience factors among healthcare workers at the beginning of the covid-19 pandemic, *Int. J. Environ. Res. Public Health*, 18, 448.

Empathic distress

resulting from helping and being empathically engaged

Moral distress

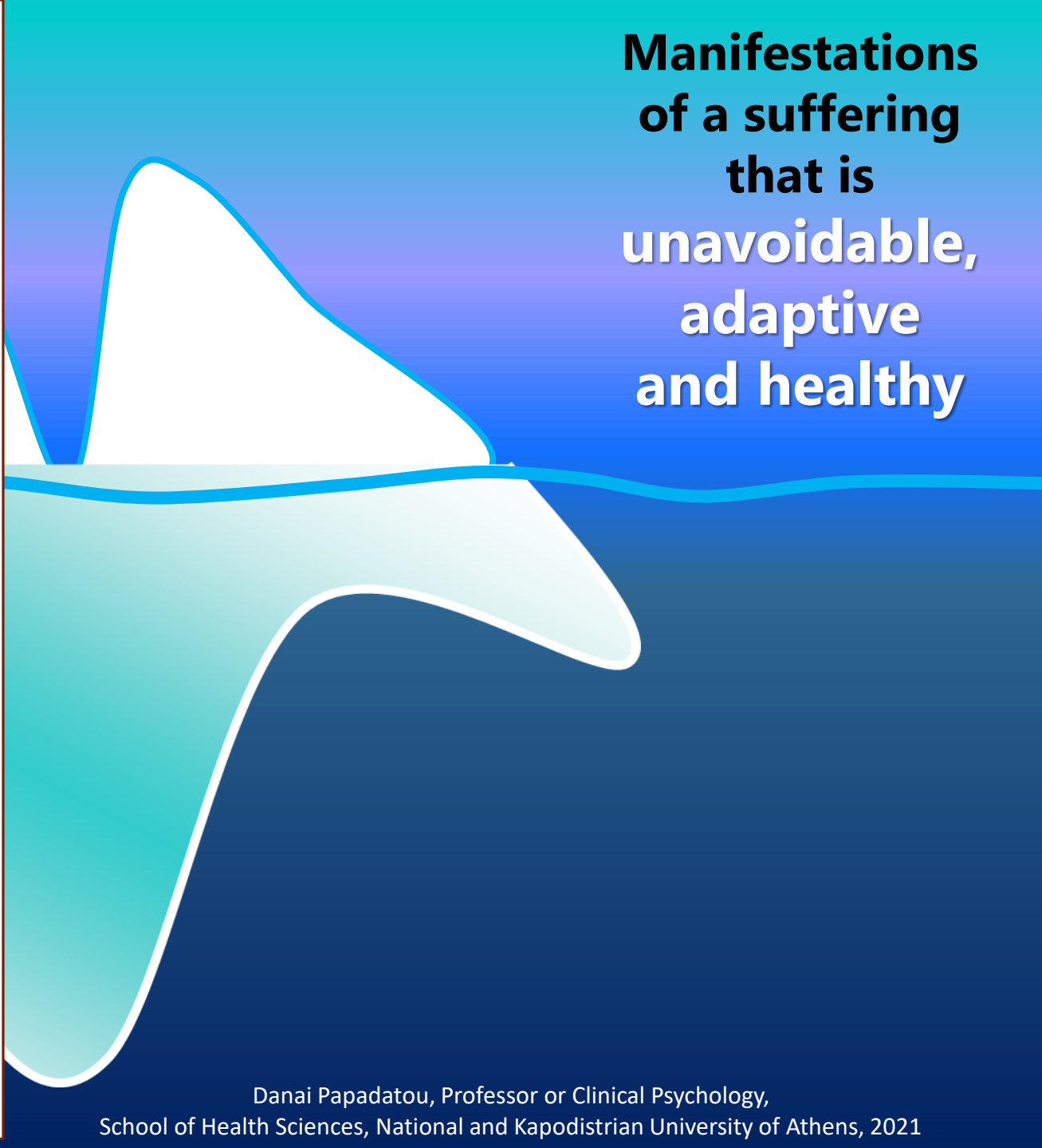
knowing the right thing to do but being unable to do it because of institutional reasons

Existential distress

experienced when confronted with our mortality & key existential issues

Grief

triggered when exposed to the dying process & death of patients and colleagues

An iceberg floating in the ocean. The tip of the iceberg, which is white, is above the water line and represents the visible manifestations of distress. The much larger part of the iceberg, which is light blue, is submerged below the dark blue water and represents the hidden, underlying causes of distress. The water surface is indicated by a wavy line.

**Manifestations
of a suffering
that is
unavoidable,
adaptive
and healthy**



According to research evidence
the most distressing experience
for HCPs is the
death of a patient

A patient's death
exposes professionals
to losses which evoke
grieving process
which is commonly
disenfranchized

American Academy of Pediatrics. Resilience in the face of grief and loss. A curriculum for medical students, pediatric residents and fellows, 2016



Ida Martinson, Danai Papadatou, Betty Chung Hong Kong, 1998

Papadatou, D. I. Martinson, Chung, P.M. (2001) *Cancer Nursing*, 24(5):

Papadatou, D., et al., (2002) *Pediatric Nursing*, 28(4): 345-353

Papadatou, D. (2001) *Bereavement Care*, 20(2): 26-29.

Papadatou D. (2000). *Omega*, 41: 59-77

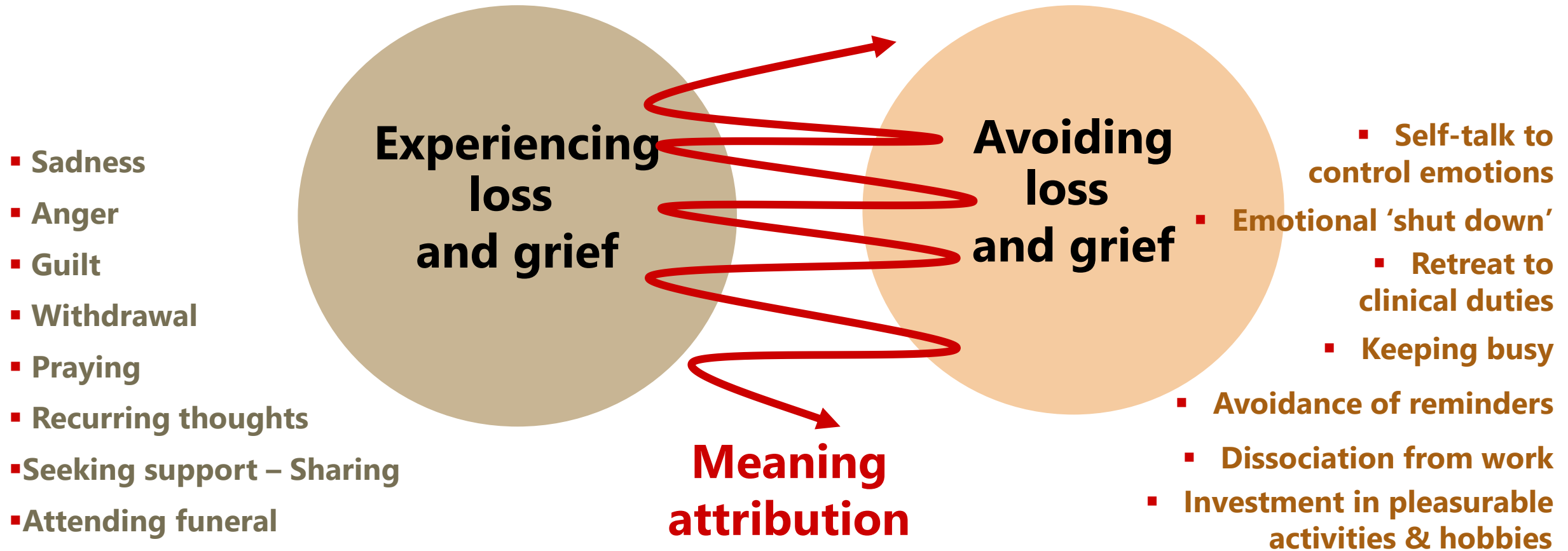
Papadatou, D. (2009). *In the face of death: Professionals who care for the dying and the bereaved*. NY: Springer

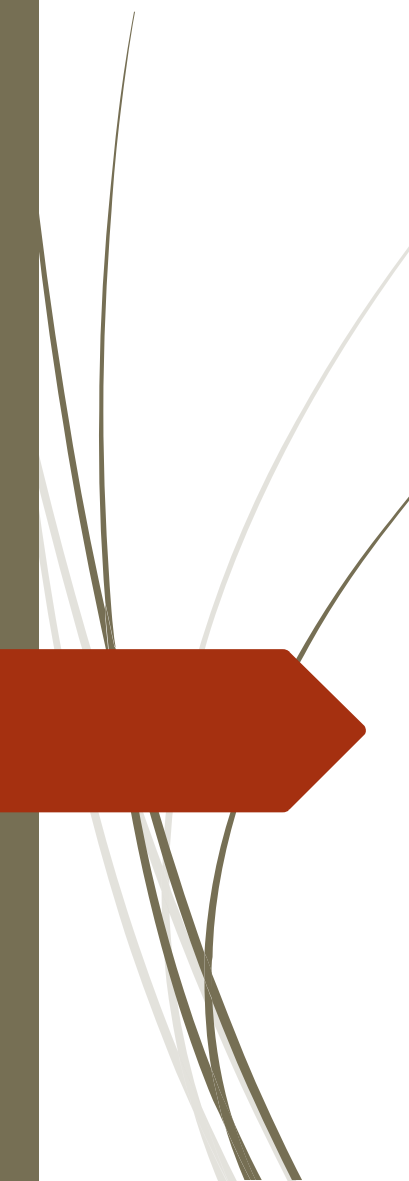
Papadatou D. (2021). Healthcare providers' responses to the death of a child. In Hain R, Goldman A, Rappaport A, Meiring M, eds. *Oxford Textbook of Palliative Care for Children*. 3rd ed. Oxford University Press

Sourkes, B., Kriewall, J., Haehl, E. Liben, S., & Papadatou, D. (2021). Witness to suffering: The clinician experience. In J. Wolfe, P. Hinds, & B. Sourkes (Eds.) In *Interdisciplinary Pediatric Palliative Care*, 2nd edition. NY: Oxford Univ Press

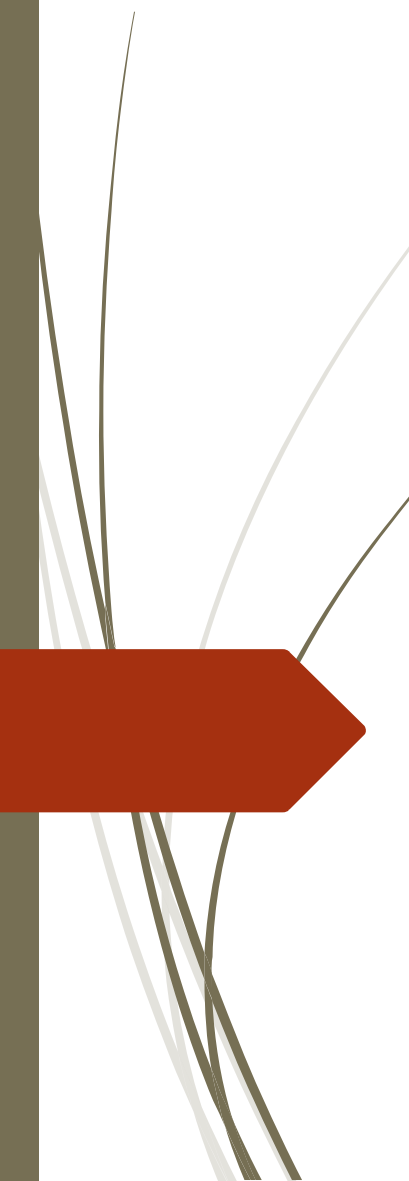
Health care professionals' grieving process

Papadatou, Martinson, Chung (2001), *Cancer Nursing*, 24,5: 402-412.





“Even though **I have tears** when a child is dying,
I hold them back because I am aware that the child
understands everything. However, the moment the patient
expires, I **cry a great deal**. I don’t know why... It’s a form of
intense release over having been there all night, over the fact
that this child has just died. This emotional release liberates
me from a heavy burden, that helps me subsequently to think:
‘What next?’ I can then **collect myself** and get into another
emotional state: *that* of my role as a nurse.....

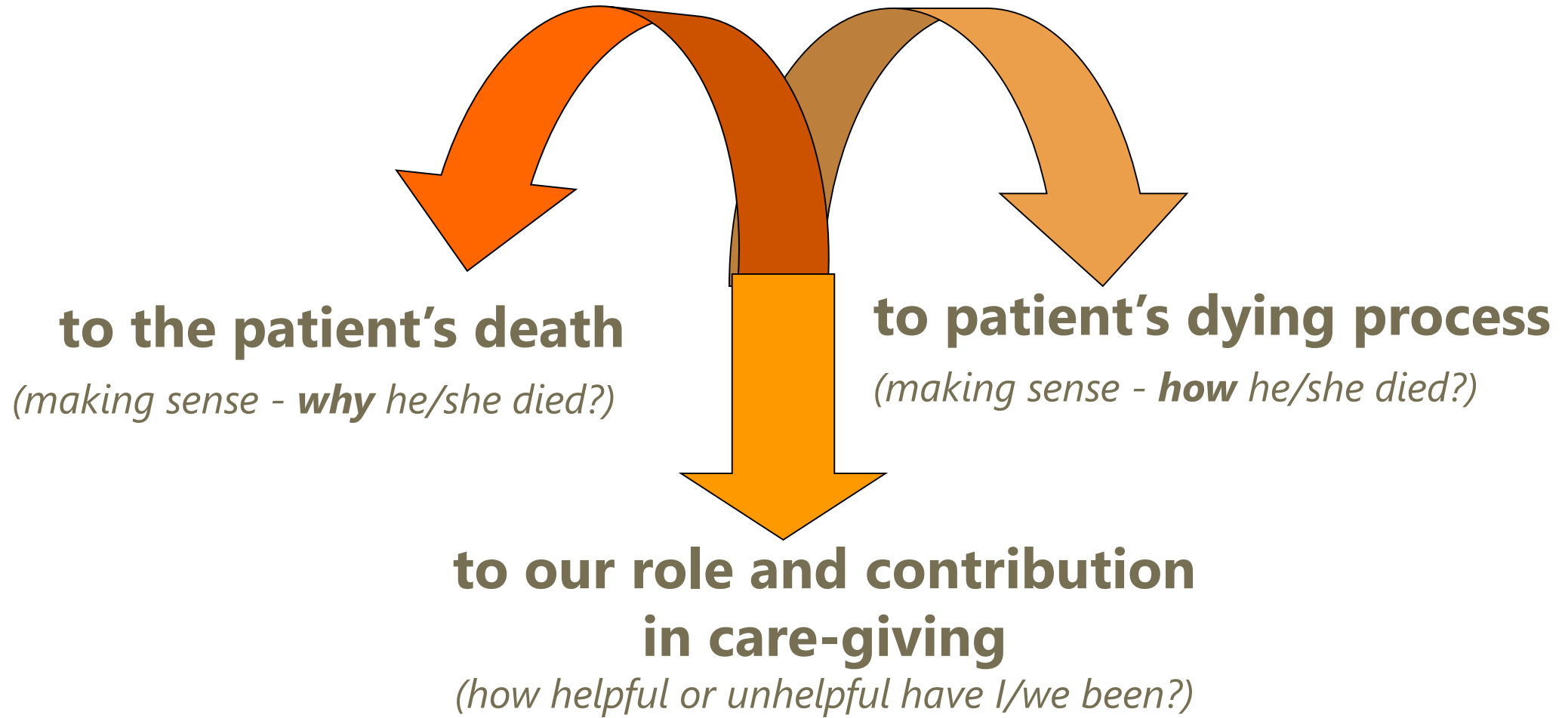


"I, then, **become a leader...** who ensures that everything is in order, who attends to the parents, to the dead body, to the unit, and to all the duties that must be carried out....

Grief does not stop the day after the child's death and is not limited to the confines of the unit. We will **remember** some of the things a particular patient did, or another child will bring back memories of our favorite one. It is as if there is an **ongoing relocation of the loss... a stirring that never stops."**

oncology male nurse

Meaning attribution



Grief complications

(e.g. chronic, traumatic, inhibited, incremental grief
& grief overload)

High vulnerability
Overwhelmed by grief



High vulnerability
Façade of invulnerability



What makes the death of a patient more “difficult”, “painful” or “complicated to cope with” than others?

- Conditions of dying and death
- Personal factors
- Relational factors
- Team factors
- Institutional/organizational work culture

Dysfunctional Team Patterns of coping with suffering

- Fragmentation of care
- Aggressive & hostile patterns
- Scapegoating
- Splitting and sub-grouping
- Non-elaboration of experiences (*anti-reflection & anti-grief patterns*)
- Collective somatization of suffering - Development of enmeshed relations with colleagues (*non differentiation*)
- Idealization of team's services (*"We are the best" syndrome*)
- Systematic avoidance of change

HCPs' stressors during the pandemic COVID-19



- ✓ **Concerns about exposure to virus, risk of infection & contamination of family/colleagues**
- ✓ Lack of access to PPE, tools, and up-to-date information
- ✓ Managing an extreme or different workload (adapting to a different workplace or work schedule)
- ✓ **Exposure to the dying process and death of patients & colleagues**
- ✓ Balancing demanding work vs family issues (e.g. child care during lockdowns, elderly care)
- ✓ Living with ongoing uncertainty about the future of the workplace or employment

E.g. Hines et al., 2021; Maunder et al., 2021; CDC, 2020, Houghton et al., 2020, Shanafelt et al., 2020;

Pandemic effects on the mental health of frontline health care professionals

- **Anxiety**
- **Depression**
- **Psychological distress**, including **post-traumatic stress**
- **Sleep disorders**
- **Physical manifestations** (headaches, lethargy, etc)
- **Burnout**

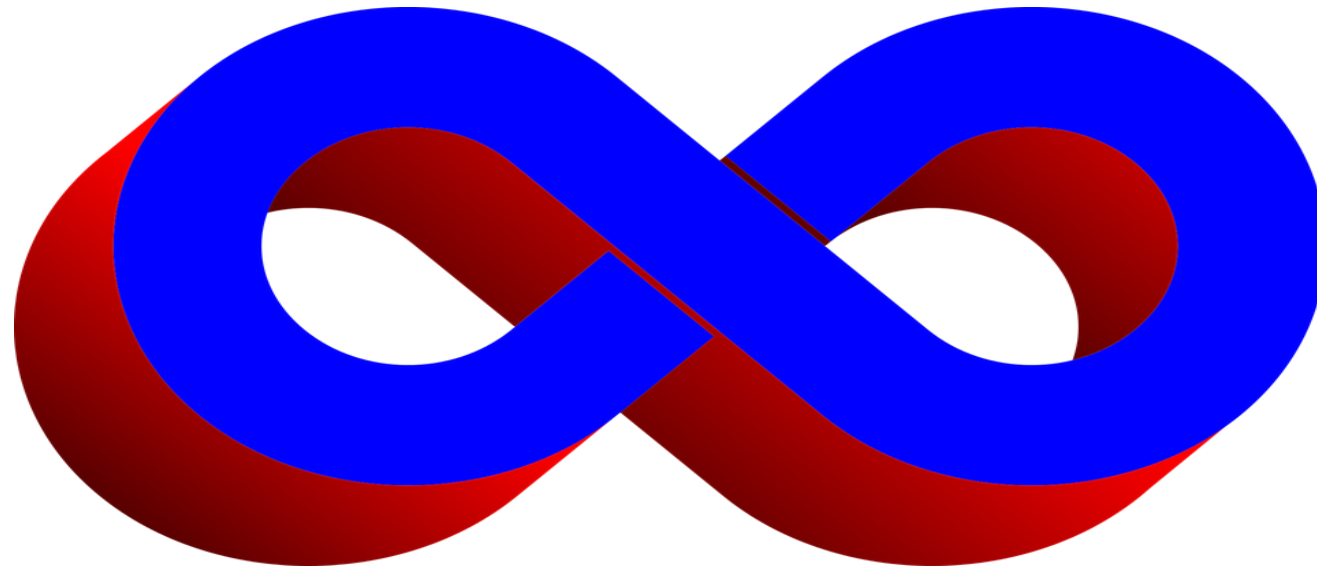
At higher risk: nurses & HCPs with children and elders at home

1st & 2nd wave (impact over time)

Maunder et al. 2021; **Hines** et al., 2021; **Naldi** et al., 2021; **Orru** et al., 2021; **Huang** et al., 2020; **Lai** et al., 2020; **Chew** et al., 2020; **Rossi** et al., 2020; **Wu** et al., 2020; Zhang et al., 2020; **Sagherian** et al., 2020; **Luceno-Moreno** et al., 2020

Both are processes which unfold in the face of adversity or distressing situations.
We are more or less vulnerable and more or less resilient
under diverse situations and
at different times in our personal and professional life

Vulnerability



Resilience

Being consumed by suffering

Relation to patients

- Low or no boundaries
- Over-identification with patients & family members
- Over-investment of relations
- Formation of dependent attachments (*need to be needed, need to be loved, to be accepted, admired, etc*)

Relation to self

- Non elaboration of personal experiences out of fear of "falling apart"
- Disconnection from self

"I have aged quickly, both biologically and psychologically as a result of working intimately with children who eventually die. Now, I experience a pressure upon my heart, a constant weight that does not allow me to breathe. I don't laugh anymore, I feel totally overwhelmed by my own pain that seems endless."

Pediatric oncologist

Appearing invulnerable

Relation to patients

- Rigid boundaries
- Formation of avoidant relationships & attachments
- Inauthentic "niceness" - Chronic detachment

Relation to self

- Non elaboration of experiences & of personal issues
- Disconnection from self – protection against suffering at any cost

"Now, I don't want to be close to any dying child or family. I cannot handle their suffering, nor my pain. I cannot even sit by their side. The silence seems very heavy. I can no longer give this tender look I used to give my patients. Whenever I give it, it's filled with despair."

Pediatric oncologist

"I close my pain in a little drawer and do not allow myself to think or feel"

Nurse

Increased vulnerability

Defensive survival mode

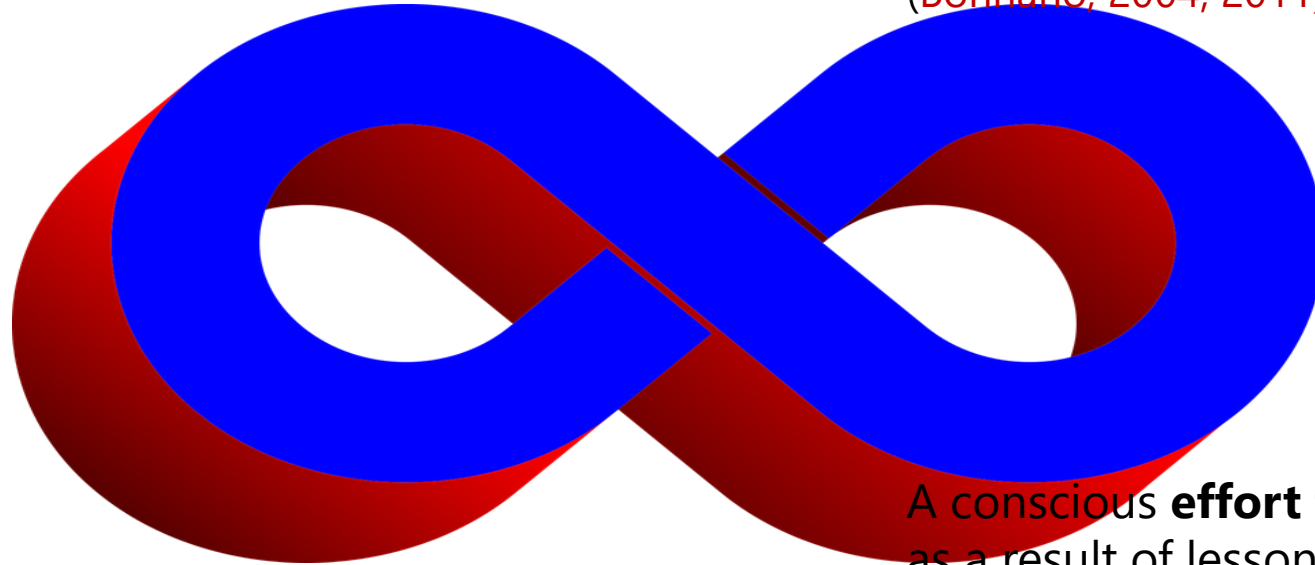
We are “**over-reactive**”
and adopt dysfunctional
coping patterns (e.g. blame,
panic, acting out, hyper alert)

We are “**hypo-reactive**”
and disconnect from self &
others (e.g. freeze, regress,
depressed, indifferent)

Disconnection from self & others

Traumatized by the effects
of the pandemic which
overwhelm resources and
challenge one's world of
assumptions

Vulnerability



Resilience

The **process** of adapting well in the face of adversity..... (American Psychological Association, 2014)

A stable **trajectory** of healthy functioning ... (Bonnano, 2004, 2011)

A conscious **effort to move forward** as a result of lessons learned from an adverse experience (Yehuda, 2010, 2013)

The **capacity** to adapt successfully to disturbances that threaten its viability, function or development (Masten, 2014)

A **process to harness resources** and sustain well-being (Panter-Brick & Leckman, 2013)

Southwick, S.M., et al. (2014). Resilience definitions, theory and challenges: Interdisciplinary perspectives *European Journal of Psychotraumatology*, 5: 25338

Increased vulnerability

RESILIENCE

Increased vulnerability



**Being consumed
by suffering**

**On being
'vulnerable enough'**

**Appearing
invulnerable**

Relations to patient/family

open, authentic relationships
characterized by empathy, compassion,
and flexible boundaries

Relation to self

self-awareness
confrontation with own mortality
acceptance of strengths & limitations
reflective learning
self-compassion

*Being “vulnerable enough”
requires a willingness
to face death,
to tolerate the anxiety
and suffering it evokes,*

*.....and to recognize that
through the care we provide
we can be transformed
by our relationship
with seriously ill & dying patients,
and by the realization
of our own mortality*

δανάη

Increased resilience

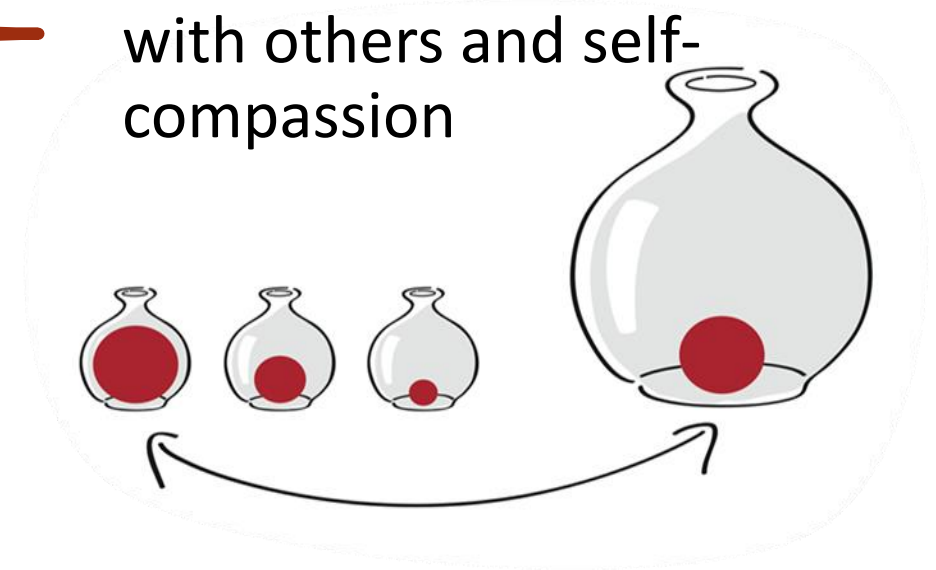
Adaptive mobilization process

HCPs mobilize effective patterns, use existing or develop resources to minimize distress (think creatively & get things done, use or create resources)

HCPs are “responsive” to what happens around them, and reflect how they affect others and are being affected in return (openness to own and others’ suffering, compassion and self-compassion)

Thrive through change ("wake up" process)

New intimacy with self, expanded self-awareness & renewed inter-connectedness with others and self-compassion





"I would never exchange
the sorrows of my heart
for the joys of the multitude.
And I would not have tears of sadness
.....turn into laughter.
I would, that my life remains
a **tear** and a **smile**.
A **tear** to unite me
with those of broken heart,
and a **smile** to be a sign
of my joy in existence".

Kahlil Gibran



Proactive interventions developed at various levels:

- ✓ Individual
- ✓ Team
- ✓ Administrative
- ✓ Institutional or Organizational

Review: 16 studies published between 2012-2020

Interventions to support the resilience of frontline health care professionals

Pollock et al., (2020) **Cochrane Database of Systematic Reviews**, 11, CD013779

- **Objective 1.** to assess the effects of interventions aimed at supporting the resilience and mental health of frontline HC&SC-Ps during and after infectious disease outbreaks
- **Objective 2.** to identify barriers and facilitators to the implementation of interventions for their support

Results: Limited evidence about what might help successful delivery of interventions. Properly planned research is urgently required.



Things to keep in mind

➤ When selecting an intervention

- ✓ Have the needs of HCPs been identified?
- ✓ Does the proposed intervention address their needs?
- ✓ Are there competent professionals to carry out the intervention?

➤ When planning & implementing an intervention

- ✓ Is there a safe work environment which promotes learning and support?
- ✓ Are there enough resources (e.g. necessary equipment, staff time, intervention costs) to implement & benefit from the intervention?

Things to keep in mind.....

➤ **When evaluating an intervention**

- ✓ Are there opportunities for HCPs to reflect on the intervention, and apply new knowledge and skills?
- ✓ Is there an evaluation process in place to assess the short and long term effects of the intervention?
- ✓ Is there a strategic plan to implement organizational changes that become apparent during the intervention?

➤ **After the pandemic is over**

- ✓ Is there time and secure conditions for an overall reflection..... meaning attribution.... "lessons learned"?
- ✓ Is there availability of support for HCPs with long-term difficulties and mental health problems?



Remember:

one type of intervention
does not fit the needs
of **all** HCPs, teams, and health care organizations

We need

flexibility

when selecting, designing
and implementing interventions
that foster resilience in health care professionals

Organizational culture

"the way of doing things around here"

It refers to
a set of behaviors & practices
shared by all members of the organization
which are driven by
specific values about how things 'ought to be'

Organizational
sub-cultures

Bowles, D. & Cooper, C (2012). The engagement work culture. UK: Palgrave Macmillan.

Papadatou, D. (2013). The private worlds of professionals, teams & organizations in palliative care. In G. Cox & R. Stevenson (Eds.) *Final Acts* Baywood

culture of care
culture of learning
culture of collaboration

Culture of care



The extent to which professionals are **emotionally held** by their organization affects their **ability to hold** individuals, families & colleagues

Bowles, D. & Cooper, C. (2012). *The engagement work culture*. UK: Palgrave Macmillan

Rezenbrink, I. (Ed.) (2011) *Caregiver stress and staff support in illness, dying & bereavement*. Oxford Press

Liben, S. & Papadatou, D. (2010) Self care. In J. Wolfe, P. Hinds, B. Sourkes (Eds.) *Textbook of interdisciplinary pediatric palliative care* (pp. 168-178). Elsevier.

Culture of Learning

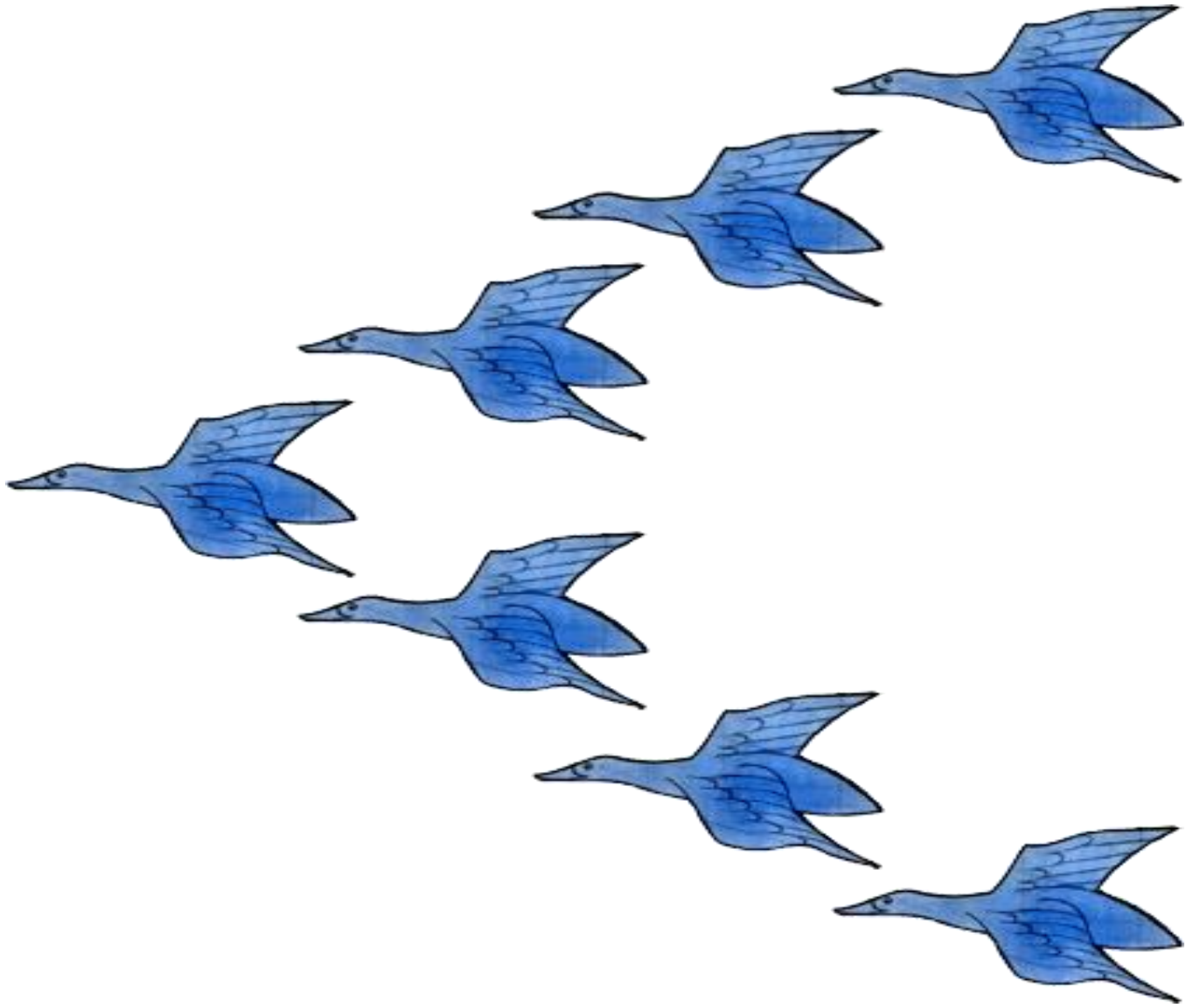


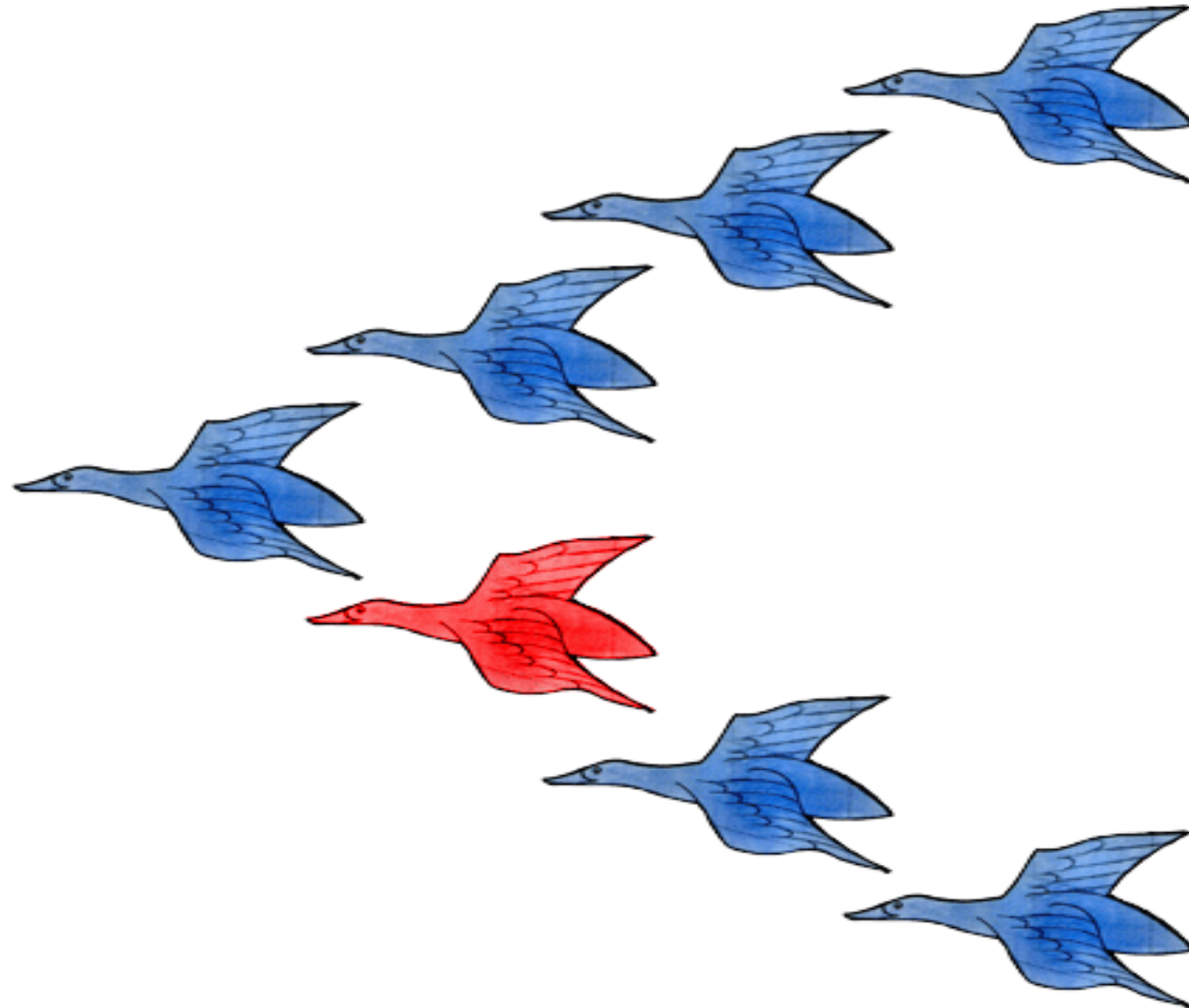
The organization sets learning as a **high priority**

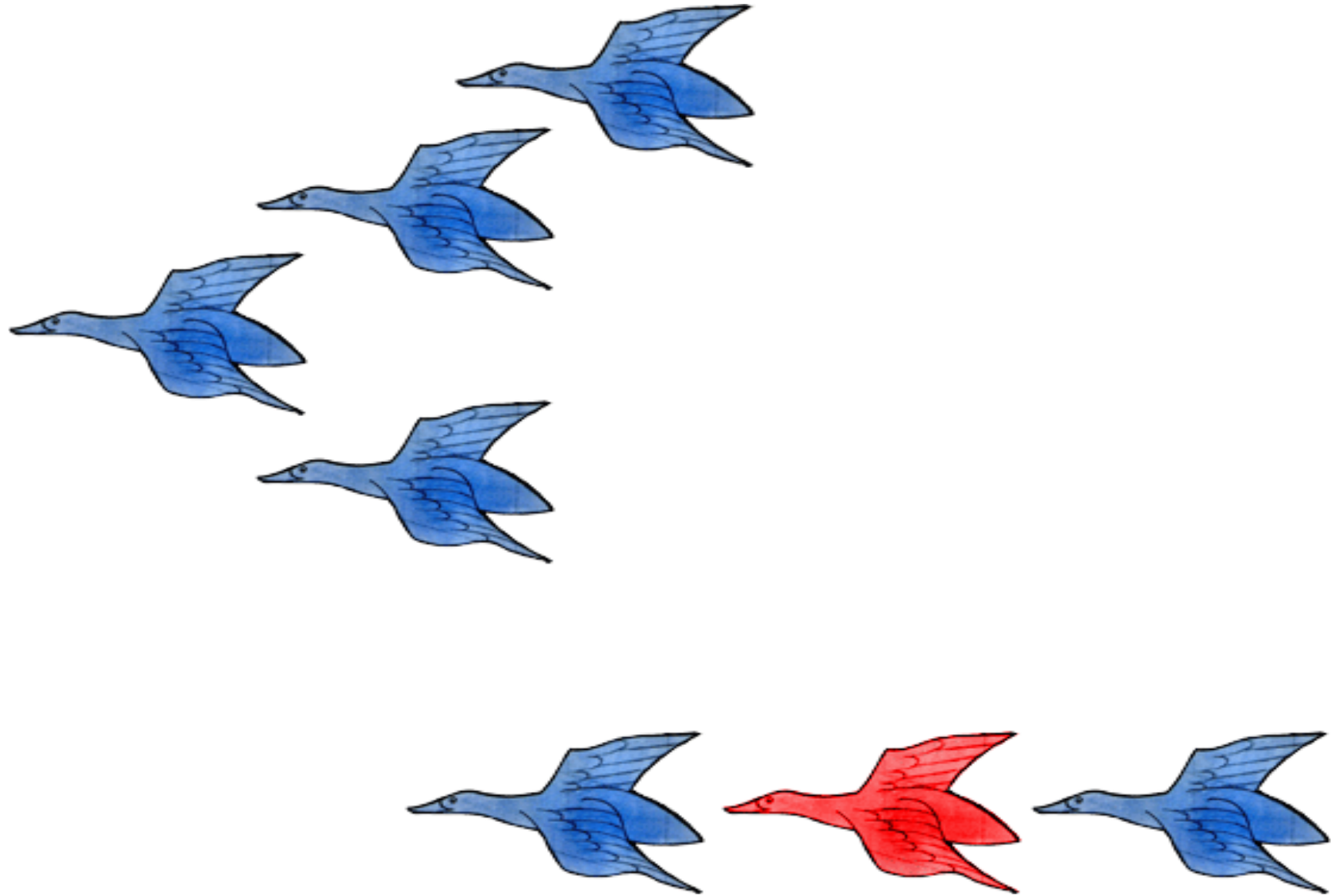
Provides **protected time** for learning **together**

Facilitates learning from **complex issues** & **regular reviews** of the team's & organization's mode of operation

culture of collaboration







Thank you



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