Value conflicts at end-of-life: navigating the intersections

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May 7, 2024

CCHCE Education Working Group

- This education session is limited in scope as it does not aim to provide solutions to conflicts arising from diverging or opposing Values at end-of-life
  - It is **aimed to kindle reflection** on the topic and bring you closer to your moral compass through discussions and deliberations.
  - This is **a safe learning space**; if any of the discussions make you feel uncomfortable, please let us know and we will provide you avenues address it.
  - There are **no one size fits all answer** to these issues, all cases need to be assessed in their own merits

Parandeh A, Khaghanizade M, Mohammadi E, Mokhtari Nouri J. Factors influencing development of professional values among nursing students and instructors: a systematic review. Glob J Health Sci. 2014 Nov 16;7(2):284-93. doi: 10.5539/gjhs.v7n2p284.; Values, Oxford Reference, available from: https://www.oxfordreference.com/display/10.1093/oi/authority.20110803115129166

Values

- Values are:
  - Are often understood in relation to morality
  - An internal reference of what is ‘good or bad’, ‘desirable or undesirable’ to ourselves and to others.
  - Based on our beliefs that determine our sense of right/wrong, drive our behavior and our interactions with others and the world.
  - Individual’s accepted internal standard of what is ‘more right or more wrong’.
  - Individual, cultural, educational, environmental and religious factors, amongst many others, including our stage of life, influence the formation and expression of our Values.

andeh A, Khaghanizade M, Mohammadi E, Mokhtari Nouri J. Factors influencing development of professional values among nursing students and instructors: a systematic review. Glob J Health Sci. 2014 Nov 16;7(2):284-93. doi: 10.5539/gjhs.v7n2p284.; Values, Oxford Reference, available from: https://www.oxfordreference.com/display/10.1093/oi/authority.20110803115129166

No conflicts of interest to declare

Learning objectives:

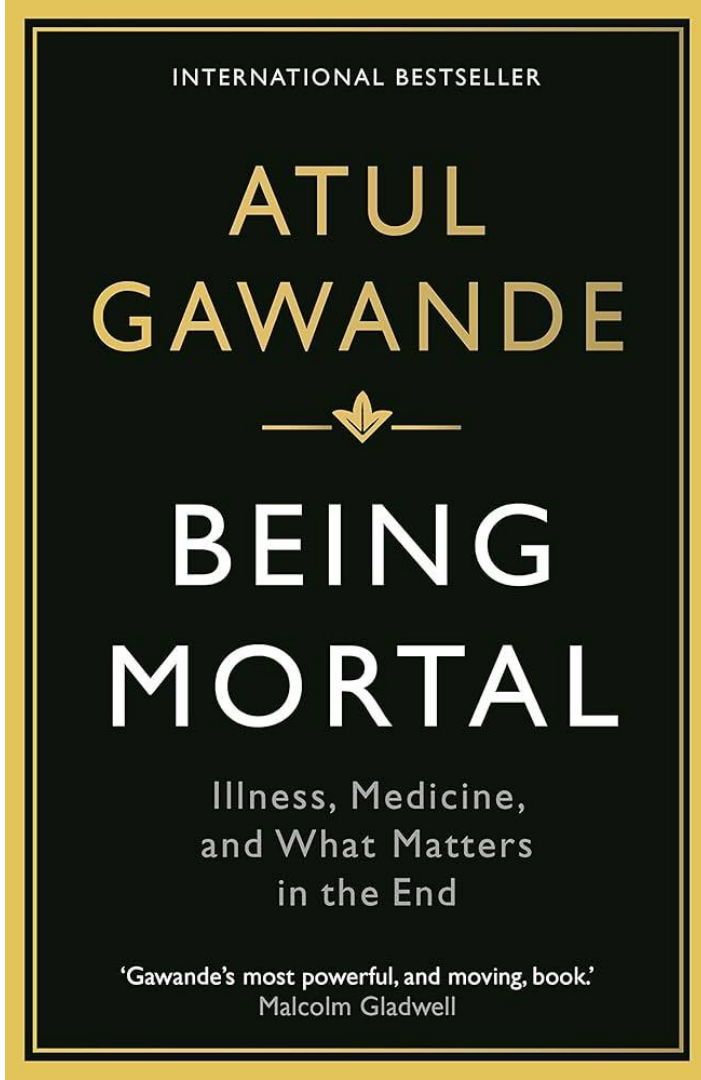
1. Reflect on Values involved at end-of-life; reflectively analyse the possible divergent and convergent individual, professional and societal values at end of life.

2. Reflect on the meaning and dimensions of suffering at end-of-life.

3. Inculcate skills to both internally and externally negotiate emerging values conflicts at end of life.

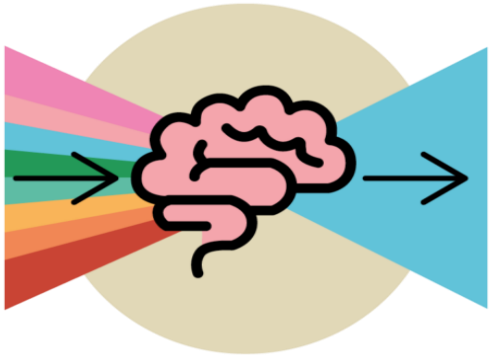
What matters most?

- "People with serious illness have priorities besides simply prolonging their lives:
  - avoiding suffering, strengthening relationships with family and friends, being mentally aware, not being a burden on others, and achieving a sense that their life is complete"
- Our system of technological medical care has utterly failed to meet these needs, and the cost of this failure is measured in far more than dollars.
- The question therefore is not how we can afford this system's expense:
  - *It is how we can build a health care system that will actually help people achieve what's most important to them at the end of their lives."*(Gawande 2014, p. 155)

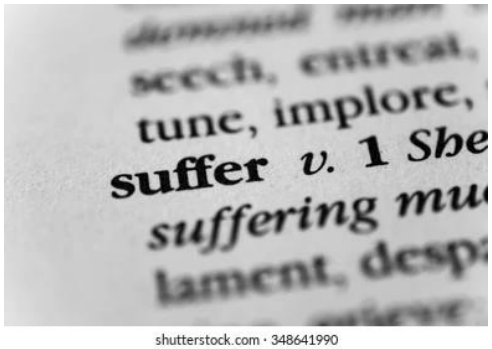


What matters most? What suffering means?

Prognosis / Current Facts/prioritized felt needs
(the reality)



Personal Value Systems
(the filter)



What suffering means at end-of-life.
(the answer)

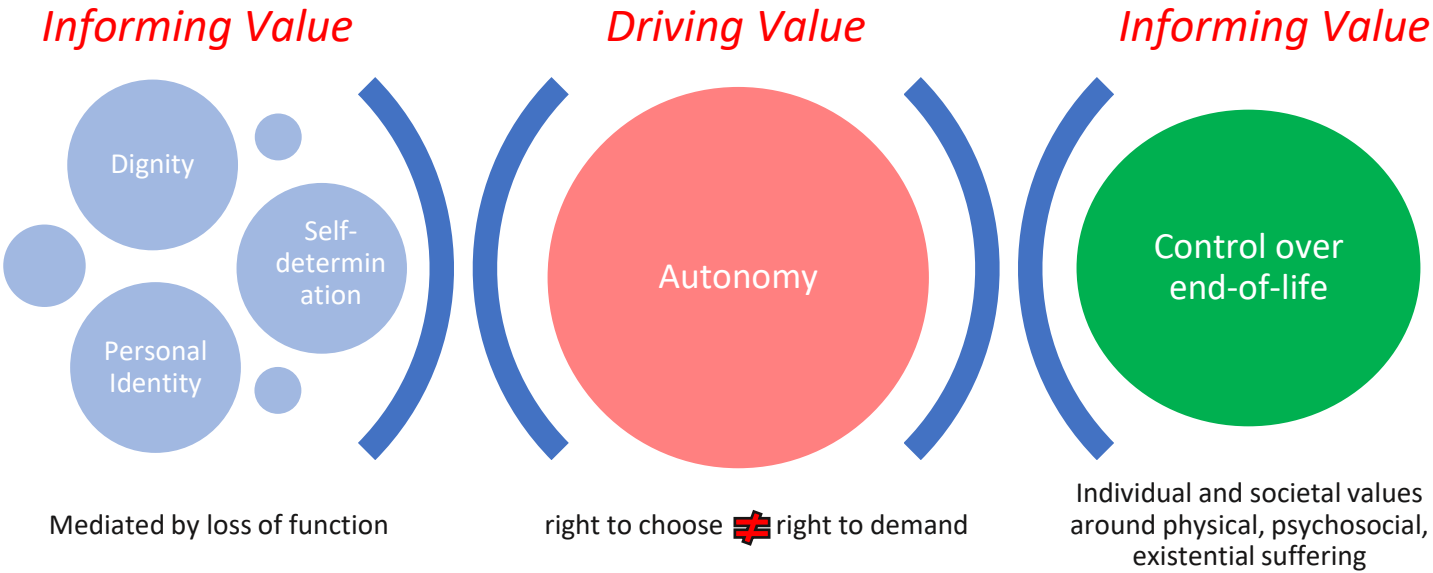
"Bodies do not suffer, People do"

Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers. JAMA. 2000;284(19):2476–2482. doi:10.1001/jama.284.19.2476

Patient and Family Values Systems

A way through which patients and families view values during end-of-life conversations

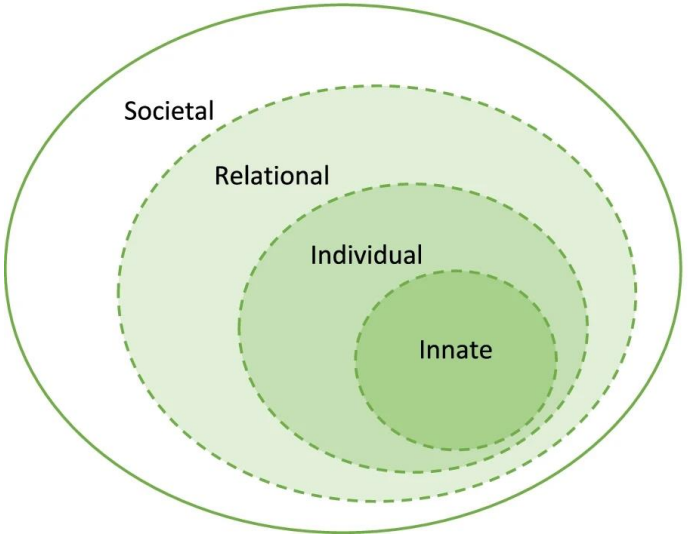
A patient's internal compass at end-of-life



Rodríguez-Prat A, Monforte-Royo C, Porta-Sales J, Escribano X, Balaguer A. Patient Perspectives of Dignity, Autonomy and Control at the End of Life: Systematic Review and Meta-Ethnography. PLoS One. 2016 Mar 24;11(3):e0151435. doi: 10.1371/journal.pone.0151435.

What is dignity?

- Feeling of being worthy of respect or honour
  - Someone worthy of value
- Intrinsic or Basic Dignity
  - An irrevocable feature of personhood that does not vary on circumstance
  - Certain facts determine if you have dignity or not
- Dynamic Dignity
  - A personal quality relative to self-perception
  - Personal perception determines if you have dignity or not
- It is hard to pick a “right” definition
  - **Dignity is a fundamentally intrinsic feature** of self-worth and important value **at the end-of-life**

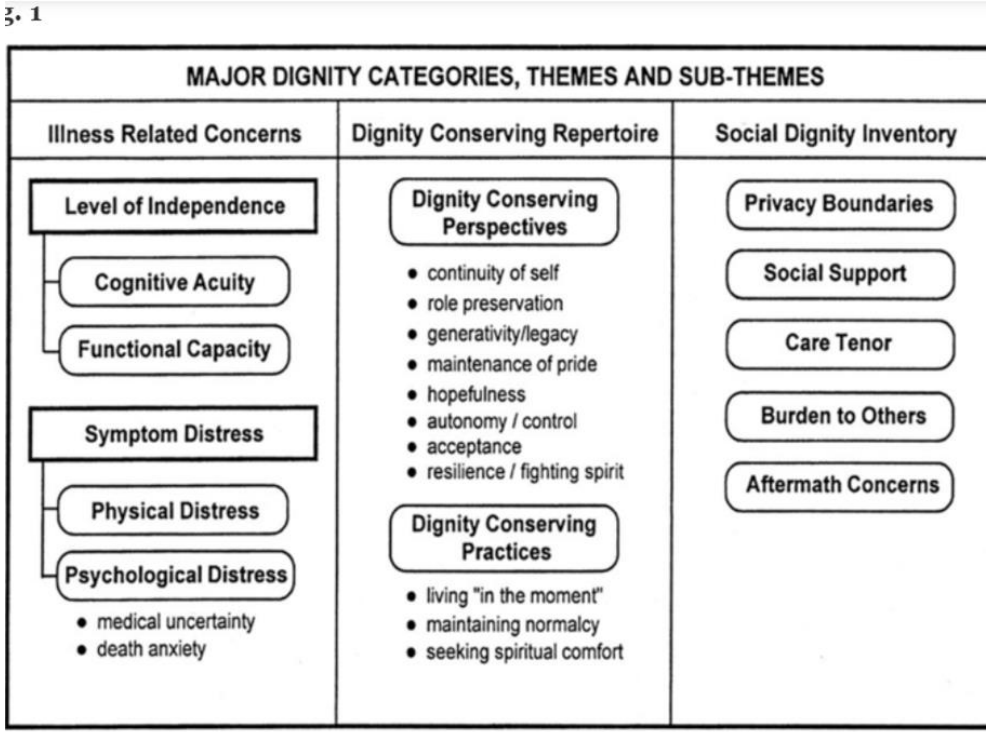


Ring Theory of Personhood that helps define dignity.

Rodríguez-Prat A, Monforte-Royo C, Porta-Sales J, Escribano X, Balaguer A. Patient Perspectives of Dignity, Autonomy and Control at the End of Life: Systematic Review and Meta-Ethnography. PLoS One. 2016 Mar 24;11(3):e0151435. doi: 10.1371/journal.pone.0151435.; Chua, K.Z.Y., Quah, E.L.Y., Lim, Y.X. *et al.* A systematic scoping review on patients’ perceptions of dignity. *BMC Palliat Care* 21, 118 (2022). https://doi.org/10.1186/s12904-022-

Dignity at end-of-life

- Human Right (WHO, 2022)
- Dignity in contemporary era- equality in worth (Barclay, 2016).
- Chochinov's model of dignity: illness related concerns, the dignity conserving repertoire, and the social dignity inventory (Chochinov et al., 2002)
- Evidence of positive impact on hope, dignity related distress and quality of life (Walundari et al, 2024)



Chochinov Model of Dignity [19, 20] with permission from the developer

World Health Organization: Active ageing: a policy Framework. 2002; Available from: http://apps.who.int/iris/bitstream/handle/10665/67215/WHO_NMH_NPH_02.8.pdf;jsessionid=A07D10E8DE1D5147F5403292E52D70E9?sequence=1. ; Barclay L. In sickness and in dignity: a philosophical account of the meaning of dignity in health care. Int J Nurs Stud. 2016;61:136–41; Chochinov HM. Dignity-conserving care--a new model for palliative care: helping the patient feel valued. JAMA. 2002;287:2253–60; Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M. Dignity in the terminally ill: a developing empirical model. Soc Sci Med. 2002;54:433–43.

Dignity Care Intervention (DCI)

- PDI (Patient dignity Inventory (26 items).
- Commonly done at home/hospice by palliative care nurse trained in DCI, but one feasibility study in Austria Hospital-duration of stay a barrier.
- Divergent theoretical and cultural congruence
  - Asian perspective: a person's worth was the core meaning of their dignity, unawareness of death is a relevant concept of 'good death' in Japan-lower participation in Japan as compared to western world.
- Particularly helpful in someone who wants to leave behind a legacy-producing a generativity document.
- Sense of purpose and continuity of self are major deliverables apart from reduction in worries around death and dying, apart from comfort and meaning to family members.


FREE ACCESS | Palliative Care | August 20, 2005

Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life

Authors: Harvey Max Chochinov, Thomas Hack, Thomas Hassard, Linda J. Kristjanson, Susan McClement, and Mike Harlos | AUTHORS INFO & AFFILIATIONS

Publication: Journal of Clinical Oncology • Volume 23, Number 24 • https://doi.org/10.1200/JCO.2005.08.391

McIlfatrick S, Connolly M, Collins R, et al. Evaluating a dignity care intervention for palliative care in the community setting: community nurses' perspectives. Journal of Clinical Nursing. 2017 Dec;26(23-24):4300-4312. DOI: 10.1111/jocn.13757.;

Patient autonomy and end-of-life care

Patient autonomy at end-of-life-what does it mean?

- Core value of ‘self-governance’
- The last chance to regain power over an illness or unwinnable situation
- Decision making focused exclusively on self-governance at end of life: either praised OR criticized
  - Does it align with experiences and preferences that ‘ought to be’ at end-of-life?
- Concept of relational autonomy, shared decision making and advance care planning
  - Dialogue between lived reality and internal construct of self-government.
  - Autonomous decision, as exercised by patients existing social and cultural milieu
  - Exercise of autonomy in the context of a diverse and highly influential relational environment.
  - Not binary or ‘all or nothing’ notion.

Gómez-Vírseda, C., de Maeseneer, Y. & Gastmans, C. Relational autonomy in end-of-life care ethics: a contextualized approach to real-life complexities. BMC Med Ethics 21, 50 (2020). https://doi.org/10.1186/s12910-020-00495-1; Gómez-Vírseda C, de Maeseneer Y, Gastmans C. Relational autonomy: what does it mean and how is it used in end-of-life care? A systematic review of argument-based ethics literature. BMC Med Ethics. 2019;20(1):76.

Relational Autonomy

- A social and communal understanding of self-governance
- People have relationships and responsibilities that impact how they will choose to act
  - Often these bonds are chosen and impact us in many ways
- Q: Can you get up and leave this presentation right now and hop on a plane to a tropical vacation?
  - Duties to your organizations
  - Duties toward your patients
  - Duties towards the presenters and organizers
  - Does this mean you lack freedom to self-govern?

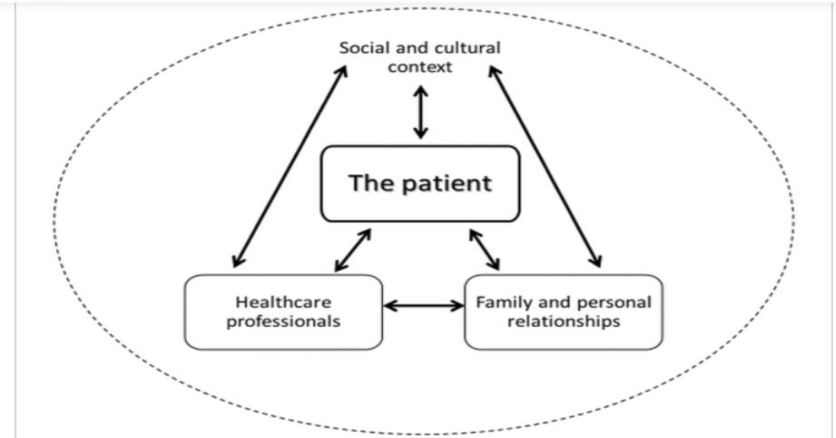
Importance of dialogue to respect RA

Dialogue is between:

- **Self-determination** determined by
  - freedom conditions (example social and political constraints)
  - Opportunity conditions (social environment that allows to make choices) AND
- **Self-governance** determined by
  - Competence conditions and
  - Authenticity conditions (example, non-alienation from social context) AND
- **Self-authorization** determined by
  - Normative authority related to accountability, self-evaluative attitudes and social recognition.

Relational autonomy incorporates patients' competence (apart from decisional capacity), authenticity (their true desires or beliefs) and the involvement level of their significant others.

Relational autonomy in end-of-life care ethics: a contextualized approach to real-life complexities



Schematic diagram of a relational approach to patient autonomy in end-of-life decision-making. Contextualized understanding of relational autonomy emphasizes interactions of primary stakeholders and the influence of sociocultural context

"I think it's a bit overly pretentious to say that a patient has full autonomy when they're dying. Because, unless others help them, it's very difficult to be an effective agent for yourself when you're physically and mentally quite frail"
-palliative care physician, Johnson et al., 2018

Gómez-Vírseda, C., de Maeseneer, Y. & Gastmans, C. Relational autonomy in end-of-life care ethics: a contextualized approach to real-life complexities. BMC Med Ethics 21, 50 (2020). https://doi.org/10.1186/s12910-020-00495-1 ; Foo K, Lin Y, Lin C, *et al* Fostering relational autonomy in end-of-life care: a procedural approach and three-dimensional decision-making model *Journal of Medical Ethics* Published Online First: 25 March 2024. doi: 10.1136/jme-2023-109818

Relational autonomy: a case example.

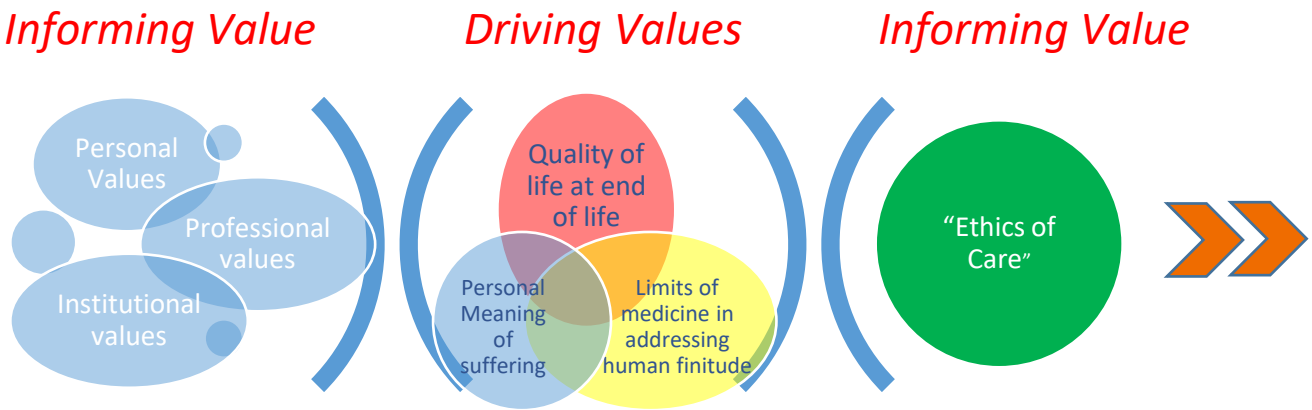
- Mr. Philip, 45-year-old with terminal cirrhosis, admitted to your palliative care unit. Only family member is his older sister, distant but cordial relationship. Self-identifies with Christian faith.
- Clinically deteriorating, but oriented, conscious, lucid, aware of his poor short-term prognosis, actively involved in end-of-life decision making. Honest discussion with you, opts for MAiD.
- After a few days, engaged with pastoral care. Extended discussion. Puts MAiD request on hold.
- A few days later…
  - Expresses moral uncertainty about his decision to the pastor.
  - Has a rectal bleed that makes him emotional
  - Acrimonious argument with sister regarding finances.
- Goes back to his decision, now wants MAiD.

Poll Q: You would:

- Say: ‘patient is undecided, wishy-washy about what he wants to do’ suggest capacity assessment.
- Say: ‘I don’t know.’ Have a family meeting with everyone, including sister and pastoral care on board.
- Say: ‘Okay. My role is not to decide which one of this multifaceted wishes at different points in time is right from a rational point of view.’ Schedule a meeting with the patient to understand how these personal preferences interact and influence each other.

Provider Value Systems

A provider's moral compass at a patient's end-of-life:



https://www.cfpc.ca/CFPC/media/Resources/Health-Policy/Guidefor-Euthanasia_EN_FInal.pdf;

Interpretations of futility at end-of-life

In ancient Greece, 'the futtilis' was a religious vessel that had a wide top and a narrow bottom. This peculiar shape caused the vessel to tip over easily, which made it of no practical use for anything other than ceremonial occasions.

Quantitative futility

- No obligation to provide a treatment that won't work/is contraindicated.
- No obligation to provide outside the 'standard of care.'
  - "ordinary, reasonable, cautious and prudent person in the position and circumstances of the defendant" do when faced with similar circumstances.
- BUT… who gets to decide what "won't work" actually means
- Typically, is value + scientific judgment
  - Will not produce a physiological effect
  - Highly unlikely to be efficacious
  - Qualitatively, the results are expected to be poor
  - Highly likely to be burdensome than beneficial
  - Speculative or untried 'treatment'
  - Warrants withdrawing or withholding treatment when weighing benefits vs. harms.
- The American Thoracic Society (ATS) joint policy statement on *Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units* endorses a strict definition of futility:
  - "intervention simply cannot accomplish the intended physiologic goal."

Qualitative futility

- The concept of qualitative futility, i.e., what sort of life is worth preserving?
- *unacceptable likelihood of achieving an effect that the patient has the capacity to appreciate as a benefit*
- Why do some families want to prolong life in a “diminished” state
- The patient may likely hear: “Your values don’t count”, although that is not said.

Suffering at end-of-life.

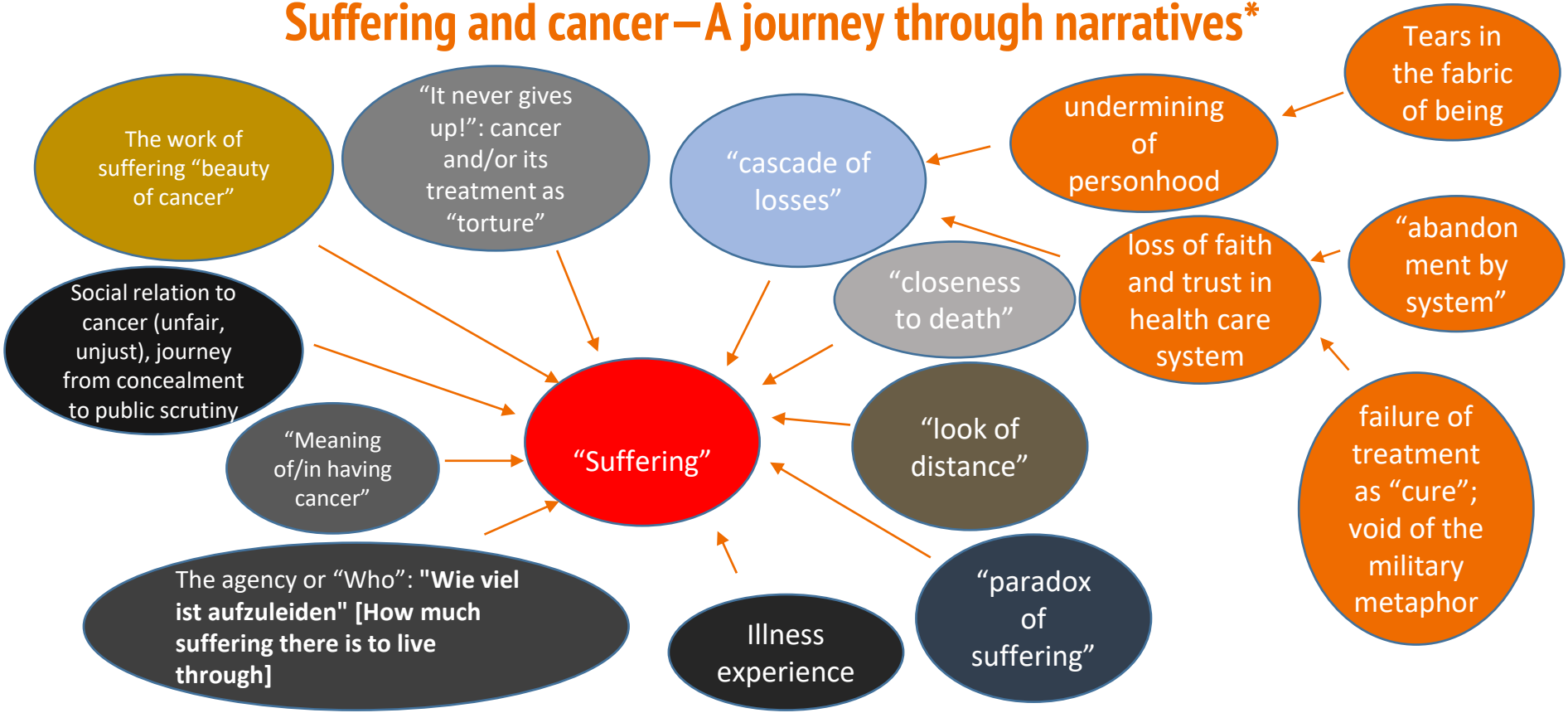
Concept, understanding, value judgments.

Journey* at end-of-life

- 55 years old, PhD, scholar, living with spouse. No children. Lost his father to cancer when his father was 51. Multiple family members died of cancer. This had led him to understand that anything beyond 50 is ‘borrowed life-years’. Very thankful to have lived up to 55.
- Diagnosed with hormone sensitive prostate cancer in June 2020. Was on regular monthly screen of PSAs for 1 year. Bone metastasis in Aug 2020. Pathological femur fracture in October 2021.
- Prognosis: Told by oncologist that 2022 should be the year of ‘maximum efforts.’ Liked the way it was reframed.
- Elements of suffering: Pain related to bone metastasis. Difficulty in letting go.

*Adopted from PSOP psychiatry consultations and modified with patient permission. Patient identifiers changed to protect privacy.

Suffering and cancer—A journey through narratives*



Gregory, D. M. (1994). *Narratives of suffering in the cancer experience* (Order No. 9517576). Available from Nursing & Allied Health Premium; ProQuest Dissertations & Theses Global. (304091477). Retrieved from https://login.proxy.bib.uottawa.ca/login?url=https://www-proquest-com.proxy.bib.uottawa.ca/dissertations-theses/narratives-suffering-cancer-experience/docview/304091477/se-2?accountid=14701

Suffering-ought we measure it?

J Nerv Ment Dis. 2021 Sep 1;209(9):615-621. doi: 10.1097/NMD.0000000000001348.

Addressing Suffering in Patients With Psychiatric Disorders

Joel Yager [1]

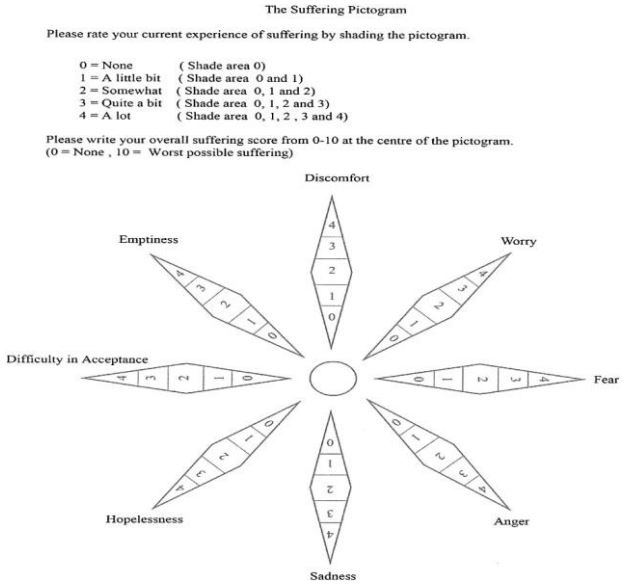
Affiliations + expand

PMID: 33857957 DOI: 10.1097/NMD.0000000000001348

Accordingly, I propose the following definition of suffering in patients with psychiatric disorders (suitable for others as well): "Suffering is the subjective experience of pervasive negative mood and psychic pain occupying most of one's mental space for a considerable length of time. Suffering is generated by sensations, feelings and reflections related to noxious experiences affecting one or more fundamental domains of human needs and motivations. These domains include biological health and disease, basic needs such as food, housing, physical safety, affiliative needs, intrapsychic and/or interpersonal issues affecting self-esteem and esteem, other goal-seeking drives, and existential aspects of life, including purpose, meaning, and transcendent perspectives."

Suffering assessment scales.

The SAQ (Encarnação et al., 2018)	Assesses four dimensions of suffering: intrapersonal and interpersonal suffering, awareness of suffering, and spiritual suffering	12-Item scale. Each item is rated on a 5-point scale ("totally agree" to "totally disagree").



Medical/Phenomenological lens to suffering

Erik Cassel's definition:

- "a state of severe distress associated with events that threaten the intactness of the person"

Cassel EJ. The nature of suffering and the goals of medicine. N Engl J Med. 1982 Mar 18;306(11):639-45. doi: 10.1056/NEJM198203183061104; Phillips, G. J. (1997). *A Phenomenology of Suffering: Reflections on Plato, Augustine, Spinoza, Nietzsche, and Heidegger* (PhD Thesis). Duquesne University ;

Hermeneutic lens to suffering

Husserl's self-embedded, 'sense-making' experience: (subjective and objective)

- mood state which potentially estranges oneself as a result of a struggle with loss of meaning and purpose in life.
- "Lived experience"

Heidegger 'being in the world'

- meaning of suffering for the individual is an integral part of suffering as an experience.

Gadamer's hermeneutic approach

- cultural, historical, temporal, personal and social contexts of the sufferer
- one's past experiences (fore-having), one's perspective (fore-sight) and one's anticipation (fore-conception).

Gadamer's Repercussions: Reconsidering Philosophical Hermeneutics. (1st ed.). University of California Press. 2004. Retrieved from http://www.jstor.org/stable/10.1525/j.ctt1pp75p;; Dallmayr, F. (2000). "The Enigma of Health:" Hans-Georg Gadamer at 100. *The Review of Politics*, *62*(2), 327–350. Retrieved from http://www.jstor.org/stable/1408040; Jardine, D. W., McCAFFREY, G., & Gilham, C. (n.d.). The Pedagogy of Suffering: Four Fragments, 9.

Praxis theory of suffering

Journey of the sufferer between two opposite behavioral states-suppressed vs. expressed

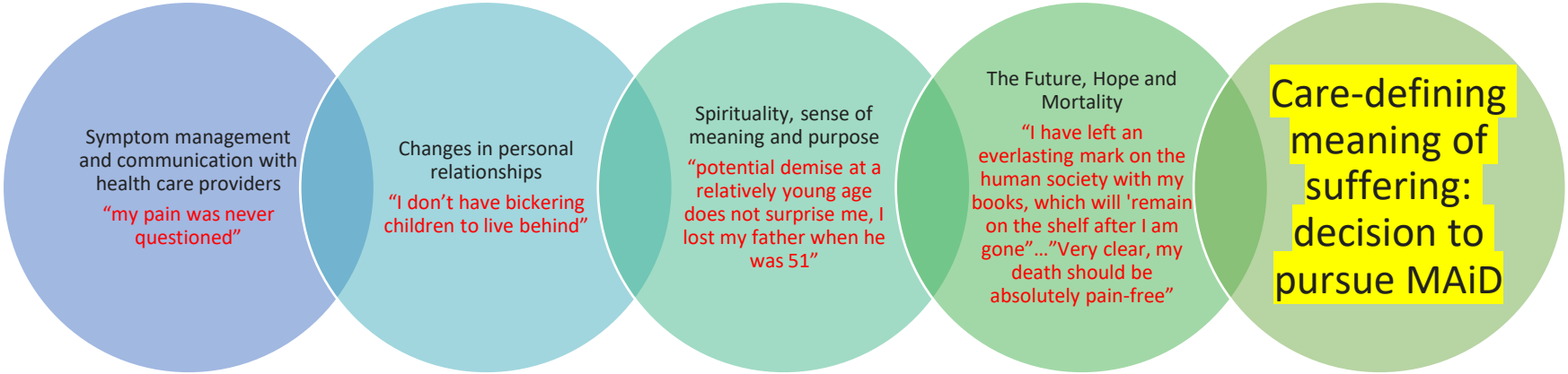
Georges, J. M. Suffering: toward a contextual praxis. ANS. Advances in Nursing Science.1997; 25(1), 79–86

Social approach to understanding suffering

dialect with respect to suffering and society is tuned negatively towards the struggle for Justice

Kleinman A. “Everything That Really Matters”: Social Suffering, Subjectivity, and the Remaking of Human Experience in a Disordering World. The Harvard Theological Review. 1997; 90(3), 315–335. Retrieved from http://www.jstor.org/stable/1509952;

Case continued…His journey in to ‘sense-making’…



Re-defining Care

- ‘Caring is viewed as a species activity that includes everything that we do to maintain, continue and repair our ‘world’ so that we can live in it as well as possible-that would include our bodies, ourselves and our environment, all of which we seek to interweave in a complex, life-sustaining web.’
  - *Berenice Fisher and Tronto*
  - How does ‘Care’ get defined at end of life?

Joan C. Tronto (2010) Creating Caring Institutions: Politics, Plurality, and Purpose, ETHICS AND SOCIAL WELFARE, 4:2, 158-171, DOI: 10.1080/17496535.2010.484259; Tronto, Joan C. “Care as a Basis for Radical Political Judgments.” Hypatia, vol. 10, no. 2, 1995, pp. 141–149. JSTOR, www.jstor.org/stable/3810286.

Navigating the intersection of Values at end-of-life

Intersection of 2 different worlds-case reflections.

World 1

Informing Value

Dignity

Self-determination

Personal Identity

Mediated by loss of function

Driving Value

Autonomy

right to choose ≠ right to demand

Informing Value

Control over end-of-life

Individual and societal values around physical, psychosocial, existential suffering

World 2

Informing Value

Personal Values

Professional values

Institutional values

Driving Values

Quality of life at end of life

Personal Meaning of suffering

Limits of medicine in addressing human finitude

Informing Value

"Ethics of Care"

External and internal healthcare systems including social determinants of health

Case: “Not allowed to make mistakes at end of life”

31 year old, mother of 2 (6 and 4 year old). Lives with family. Rare carcinoma of one of the vestigial organs. Metastasis to peritoneum. Unable to tolerate chemotherapy. Believes surgery better than chemotherapy, ‘removes cancer cells, thereby reducing cancer load’. Underwent first surgery in Ottawa. Second was more challenging in terms of risks vs. benefits and metastasis, went to Toronto, surgeons ambivalent about benefit, on table, decided not to go ahead. Consulted a famous surgeon in USA who was willing to do it, underwent in 2023. Recently underwent it the same/similar procedure in 2024. Told survival now in months. Pain and nausea post surgery undermining QOL.

Person behind: affectionate, family person. Why undergo surgery? Do it for my children. Trust is also important value.

Engaged in dignity enhancing therapy, believes in soul continuing to exist beyond the body. Currently engaged in designing video messages for children.

Case continued

Regularly visited by palliative care at home for pain and nausea.

Pain crisis last week. Supposed to have crisis medications, no supplies in the box by mistake. She wanted it, so that children do not have to see her going to the hospital in an ambulance. Nurses ‘did not know how to help her, although they tried their best’. 911 called. Children saw her go to the hospital in an ambulance. She could not see her children suffer as they saw her going to the hospital. Pain relief provided in the hospital.

Back at home:

-if this happens again, I will likely have no/less control. Should I chose MAiD? Initially never wanted MAiD as ‘did not want family to go through it’ , but now, wondering if MAiD is a better option.

You:

- provide an empathetic understanding of the situation, pull up your team for the error, promise ‘this will never happen again’.
- provide an empathetic understanding of the situation, reflect on which the two outcomes (pain being out of control again and she not having immediate access) vs. she opting for MAiD lies closer/farther from her her core value systems.
- provide an empathetic understanding of the situation, reflect how your values are against MAiD and that you will refer her to your colleague who understands MAiD and will help navigate it.

Summarizing:

- -Values trade offs at end-of-life are common and are a source of emotional, existential and personal distress.
  - Common trade offs involve diverging/converging values of dignity, need for control, respect for autonomy, amongst others.
  - The meaning of suffering at end-of-life is shaped by a nebulous intersection of Values unique to an individual.

- Lenses helpful to navigate Value conflicts:
  - Relational autonomy lens.
  - Dignity enhancing lens.

Thank you!

-reflections, Individual take home messages.