



End-of-Life Conversations with Patients and Caregivers

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Disclosures

- We have no relevant disclosures.

This presentation and/or comments will provide a balanced, non-promotional, and evidence-based approach to all diagnostic, therapeutic and/or research related content.

Cultural Linguistic Competency (CLC) & Implicit Bias (IB)

The following CLC & IB components will be addressed in this presentation:

- Cultural differences in the perception of end of life.
- Cultural differences and spiritual beliefs in the perception of end of life and how we can improve our approaches to engaging individuals of diverse cultures.

Overview

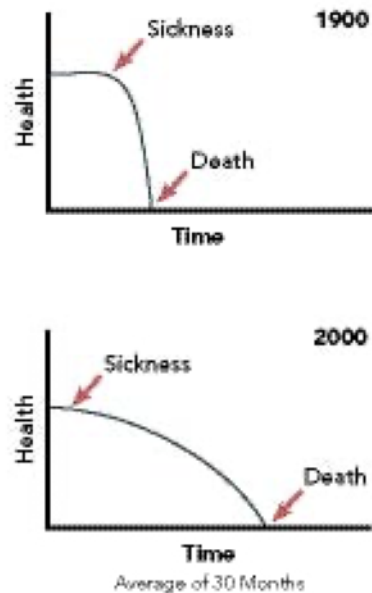
- Dying in the 21st Century
- A Good Death
- Benefits and Barriers
- Cultural Considerations
- Patient and Family Perspectives
- SPIKES Protocol
- Partnering with Social Work
- Medical Aid in Dying
- Tying It All Together
- Resources
- References



Dying in the 21st Century

DYING TRAJECTORIES FROM 1900 AND 2000

Dying has become more complex and takes longer.



Source: Corr CA. Death in modern society. In: Doyle D, Hanks G, MacDonald N, eds. *Oxford Textbook of Palliative Medicine*. 2nd ed. New York, NY: Oxford University Press Inc; 1998:31-40.

- Most discussions of EOL preferences do not occur until approximately 1 month before death, despite most patients desiring this information earlier. (Balaban, 2000).
- Predicting life expectancy is one of the biggest challenges in end-of-life care (Christakis et al., 2000).
- Up until the mid 1940's, most individuals died at home. Care for the elderly and dying has now shifted to skilled nursing facilities and hospitals (Old, 2008).

What is a "Good Death"?

- How we define a good death is unique to each of us and is influenced by our:
 - Age, gender, race, socioeconomic status,
 - Culture, values, beliefs,
 - Life experience
- When asked about end-of-life preferences, patients often report:
 - Being free from pain
 - Maintaining dignity
 - Not becoming a burden (practical/financial/emotional)
 - Dying at home, surrounded by family/close friends

“How we seek to spend our time may depend on how much time we perceive ourselves to have.”

— Atul Gawande

Benefits of End-of-Life (EOL) Discussions

- Initiates the opportunity to start learning (together) how the patient defines a good death.
- Provides a safe space for patients to share anxieties/fears – fear of pain and suffering, fear of death
- Allows for family/caregivers to hear from their loved ones about what is most important to them
- Avoids unwanted or overly aggressive procedures that are not aligned with patient's values
- Promotes earlier hospice enrollment – better quality of life for patients/more support for caregivers
- Improves bereavement outcomes for family/caregivers

Barriers to EOL Discussions

The Physician's Perspective

- Lack of training, comfort and **time**
- Uncertainty about prognostication accuracy – fear of harming the patient
- **Managing the emotional and behavioral reaction of patients/families**
 - Not wanting to extinguish hope in patients
 - Fearing patient will feel abandoned
- Lack of patient's capacity to make goals-of-care decisions
- **Patients/families with unrealistic expectations – difficulty accepting poor prognosis**
- Patient/family's difficulty with understanding the limitations of life-sustaining treatments (e.g., CPR, intubation)

Bernacki RE, Block SD, for the American College of Physicians High Value Care Task Force. Communication About Serious Illness Care Goals: A Review and Synthesis of Best Practices. JAMA Intern Med. 2014;174(12):1994–2003. doi:10.1001/jamainternmed.2014.5271

Cultural Considerations

- The importance of language preference, immigration status, and health literacy cannot be understated (Costas-Muniz et al., 2020).
- In traditional Chinese culture, discussion of death and dying is taboo and thought to bring bad luck to one's family (Lee et al., 2018).
- Medical interpreters can act as cultural brokers, advocating for patients and caregivers during the encounter by sharing cultural information with both parties to help clarify the transmitted message. They can address terms or concepts that are untranslatable or may not exist in the culture using the target language (Silva et al., 2020).
- In some cultures, decision-making involves the whole family, especially Latino culture. This can at times be a barrier to completing an advance directive as it only allows for naming one power of attorney and one alternate power of attorney (Carr, 2011).
- It is not unusual in Muslim culture to find that family members may prefer that the patient not be directly informed about a life-threatening prognosis or diagnosis (Al-Jahdali et al., 2012).
- In a study of a diverse group of patients with advanced cancer, religiousness was associated with wanting all measures to extend life, even after adjustment for race and ethnicity. In focus groups, Latino surrogates indicated that suffering was to be borne as part of a test of faith (Smith et al., 2009).
- Latino culture and end-of-life care include three important factors: inclusion of family in decision-making, spirituality, and fatalismo (belief in fate; one's future is not in our control) (Smith et al. 2009)

Patient and Family Perspectives

Connecting with Care

- According to caregivers, effective communication should include active listening as its primary element. Patients appreciate conversations where the physician is attentive, calm and not pressed for time, and they prefer they refrain from large, incomprehensible words.
- Patients and caregivers have expressed appreciation for *social workers* or other members of the multidisciplinary team for starting the conversation.
- Many patients have expressed having it on their mind but feeling uncertain of how to bring it up
- Family/caregivers find these conversations more challenging when they take place in a hallway
- Some families expressed feeling pressured to make decisions immediately following end-of-life conversations; allowing them time to process and come to a decision is most effective.

“The tricky part of illness is that, as you go through it, your values are constantly changing. You try to figure out what matters to you, and then you keep figuring it out... Death may be a one-time event but living with terminal illness is a process.”

-Paul Kalanithi, When Breath Becomes Air

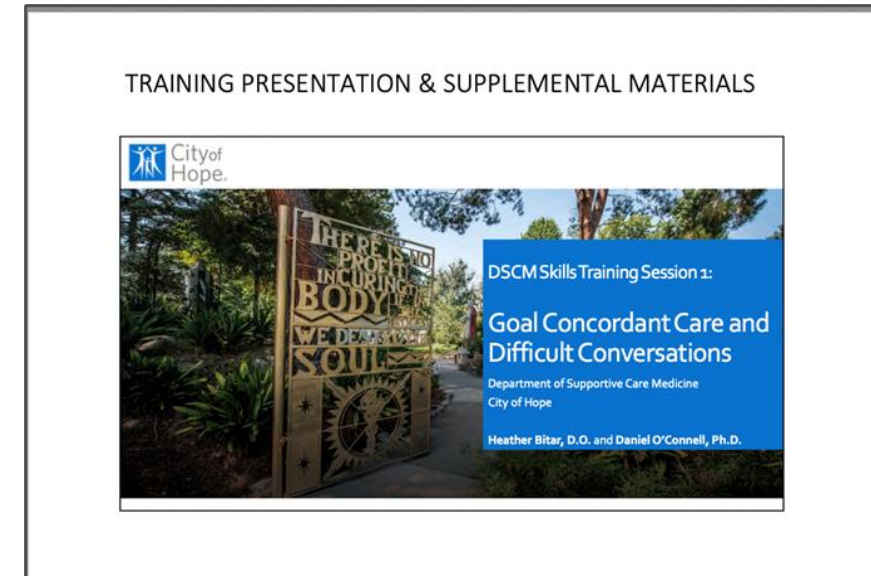


SPIKES Protocol

A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer

1. Step 1: **S**—**SETTING UP** the Interview
2. Step 2: **P**—Assessing the Patient's **PERCEPTION**
3. Step 3: **I**—Obtaining the Patient's **INVITATION**
4. Step 4: **K**—Giving **KNOWLEDGE** and Information to the Patient
5. Step 5: **E**—Addressing the Patient's **EMOTIONS**
6. Step 6: **S**—**STRATEGY** and **SUMMARY**

“In particular, SPIKES emphasizes the techniques useful in responding to the patient’s emotional reactions and supporting the patient during this time.” –Baile et al., 2000



Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist*. 2000;5(4): 301-11. doi: 10.1634/theoncologist.5-4-302. PMID: 10964998.

Partnering with Social Work

*Teaming up with Social Work can **maximize physician time** for successful conversations by:*

- Exploring patients' values and goals through advance care planning tools
- Providing insight about family dynamics and cultural considerations
- Assessing patient/family's understanding of diagnosis, prognosis and treatment options
- Managing complex emotions during end-of-life discussions
- Remaining with family after end-of-life discussions to process and/or continue the discussion



Medical Aid in Dying: An Invitation to Talk

- What is Medical Aid in Dying (MAID)?

A trusted and time-tested medical practice that allows a terminally ill, mentally capable adult, with a prognosis of six months or less to live, to request from their doctor a prescription for medication they can decide to self-ingest to die peacefully in their sleep.

California End Of Life Option Act (EOLOA): June 9, 2016

Allows terminally ill, mentally capable adults, with 6 months or less to live, to request a doctor's prescription for medication that they could decide to take in their final days or weeks to end unbearable suffering and die peacefully.

- MAID is not assisted suicide, suicide or euthanasia.



Reasons Patients Request MAID

Characteristics	2021		2020		1998–2019		Total	
	(N=238)		(N=259)		(N=1,662)		(N=2,159)	
End-of-life concerns ⁶								
Losing autonomy	222	(93.3)	241	(93.1)	1,499	(90.2)	1,962	(90.9)
Less able to engage in activities making life enjoyable	219	(92.0)	244	(94.2)	1,484	(89.3)	1,947	(90.2)
Loss of dignity ⁷	162	(68.1)	188	(72.6)	1,132	(73.8)	1,482	(73.0)
Burden on family, friends/caregivers	129	(54.2)	139	(53.7)	775	(46.6)	1,043	(48.3)
Losing control of bodily functions	112	(47.1)	101	(39.0)	730	(43.9)	943	(43.7)
Inadequate pain control, or concern about it	64	(26.9)	87	(33.6)	443	(26.7)	594	(27.5)
Financial implications of treatment	20	(8.4)	17	(6.6)	71	(4.3)	108	(5.0)

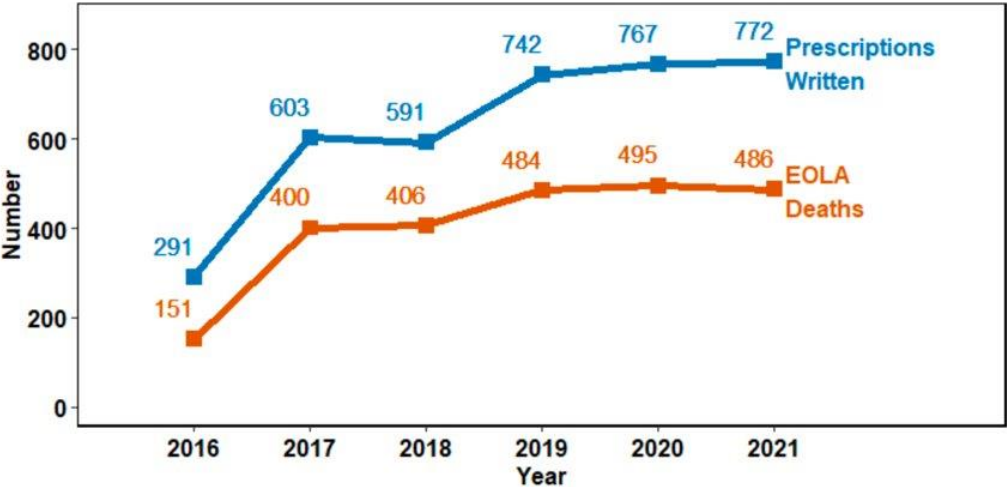
Oregon Death With Dignity Act – 2021 Data Summary
www.oregon.gov/oha

Current States with Medical Aid in Dying laws

State	Name of Act	Authorization Date	Effective Date
Oregon	Oregon Death with Dignity Act	11/8/1994	10/27/1997
Washington	Washington Death with Dignity Act	11/4/2008	3/5/2009
Montana	Baxter V. Montana	12/31/2009	12/31/2009
Vermont	Vermont Patient Choice and Control at the End of Life Act	5/20/2013	5/20/2013
California	California End of Life Option Act	10/5/2015	6/9/2016
Colorado	Colorado End of Life Options Act	11/8/2016	12/16/2016
Washington, D.C.	D.C. Death With Dignity Act	12/20/2016	2/18/2017
Hawai'i	Hawai'i Our Care, Our Choice Act	4/15/2018	1/1/2019
New Jersey	New Jersey Medical Aid in Dying for the Terminally Ill Act	4/12/2019	8/1/2019
Maine	Maine Death With Dignity Act	6/12/2019	9/19/2019
New Mexico	New Mexico Elizabeth Whitefield End-of-Life Options Act	4/8/2021	6/20/2021

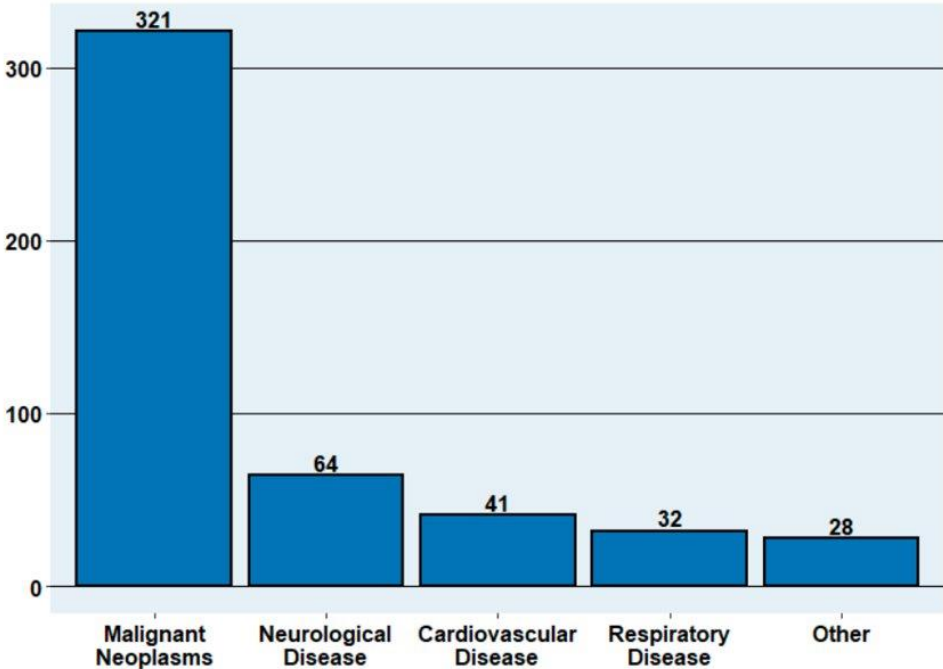
California End of Life Option Act

Figure 1: Summary of EOLA Prescriptions and Deaths 2016-2021



² Percentages presented in this Data Report are rounded to the nearest tenth. Due to rounding, percentages when totaled may not equal 100.0 percent.

Figure 3: Major Illness Categories for EOLA Individuals in 2021



Tying It All Together

- Most patients want to discuss advance care planning and they expect physicians to initiate the discussion. Using the hypothetical can be an effective starting point (Balaban, 2000):

“I would like to take a few minutes for us to begin discussing an important topic: I’d like to know how I should care for you if you become very ill.”

- Patients are most receptive when their physicians approach them with empathy and compassion
 - Enlist the expertise of your Social Workers
 - Allocate time and space for a meaningful conversation
 - Consider culture and utilize the aid of interpreters as needed
- Acknowledge and address patient’s anxiety and fear of death – open and direct conversations can alleviate fear (Gawande, 2014).

“What are your fears and worries for the future? What are your priorities if time becomes short? “ What are you willing to sacrifice and what are you not willing to sacrifice?”

Tying It All Together - continued

- Include family/caregivers and consider how decisions are made in the family; appoint a surrogate decision-maker
 - Prepares and equips the surrogate decision maker
 - Reduces the isolation experienced by the dying person
- Check in periodically throughout the treatment trajectory. Critical events such as hospitalizations or disease progression are openers to re-evaluate goals and values (Pigot et al., 2019)
- Collaborate with members of the multidisciplinary team ([social work](#), [chaplaincy](#), [palliative care](#), [nursing](#)) to work together to achieve patient's goals for a good death.



Resources

- Being Mortal – Atul Gawande - PBS Frontline, Season 2015 (<https://www.youtube.com/watch?v=IQhI3Jb7vMg>)
- California Hospice and Palliative Care Association (<https://www.calhospice.org>)
- Center to Advance Palliative Care: (<https://www.capc.org>)
- Compassion & Choices (<https://compassionandchoices.org>)
- The Conversation Project (<https://theconversationproject.org>)
- End of Life Choices California (<https://endoflifechoicesca.org>)
- SPIKES—A Six-Step Protocol for Delivering Bad News: Application to the Patient With Cancer (<http://theoncologist.alphamedpress.org/content/5/4/302>)
- What makes life worth living in the face of death – Lucy Kalanithi – Ted Talk (<https://www.youtube.com/watch?v=U5-yBjKKicA>)

Questions

THANK YOU!

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