

Maine PA conference

Having the tough talk with patients and families in your care.

Sunday River

February 7th, 2019

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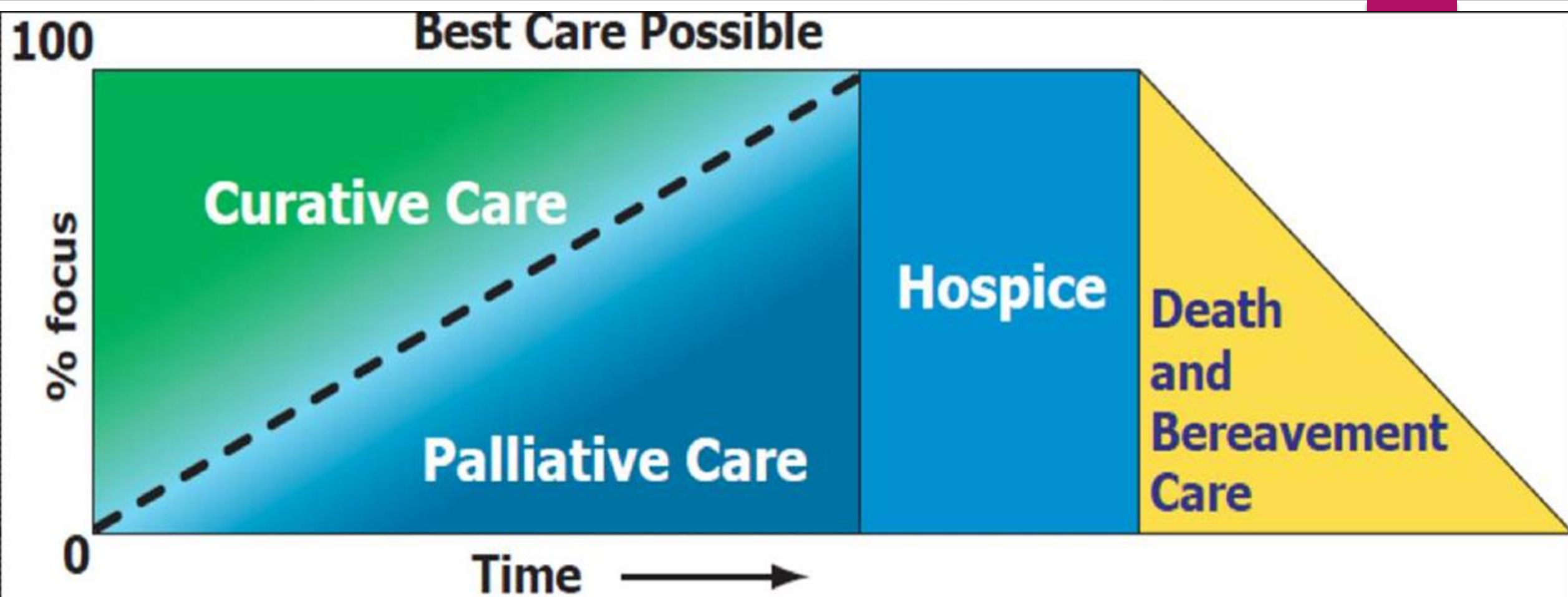
Dr. Shauna McElrath, DO

Objectives

- 1. Explore the differences between palliative care and hospice**
- 2. Discuss useful methods to address difficult conversations about goals of care**
- 3. Identify language to use and language to avoid when discussing resuscitation wishes/code status**

What is palliative care?

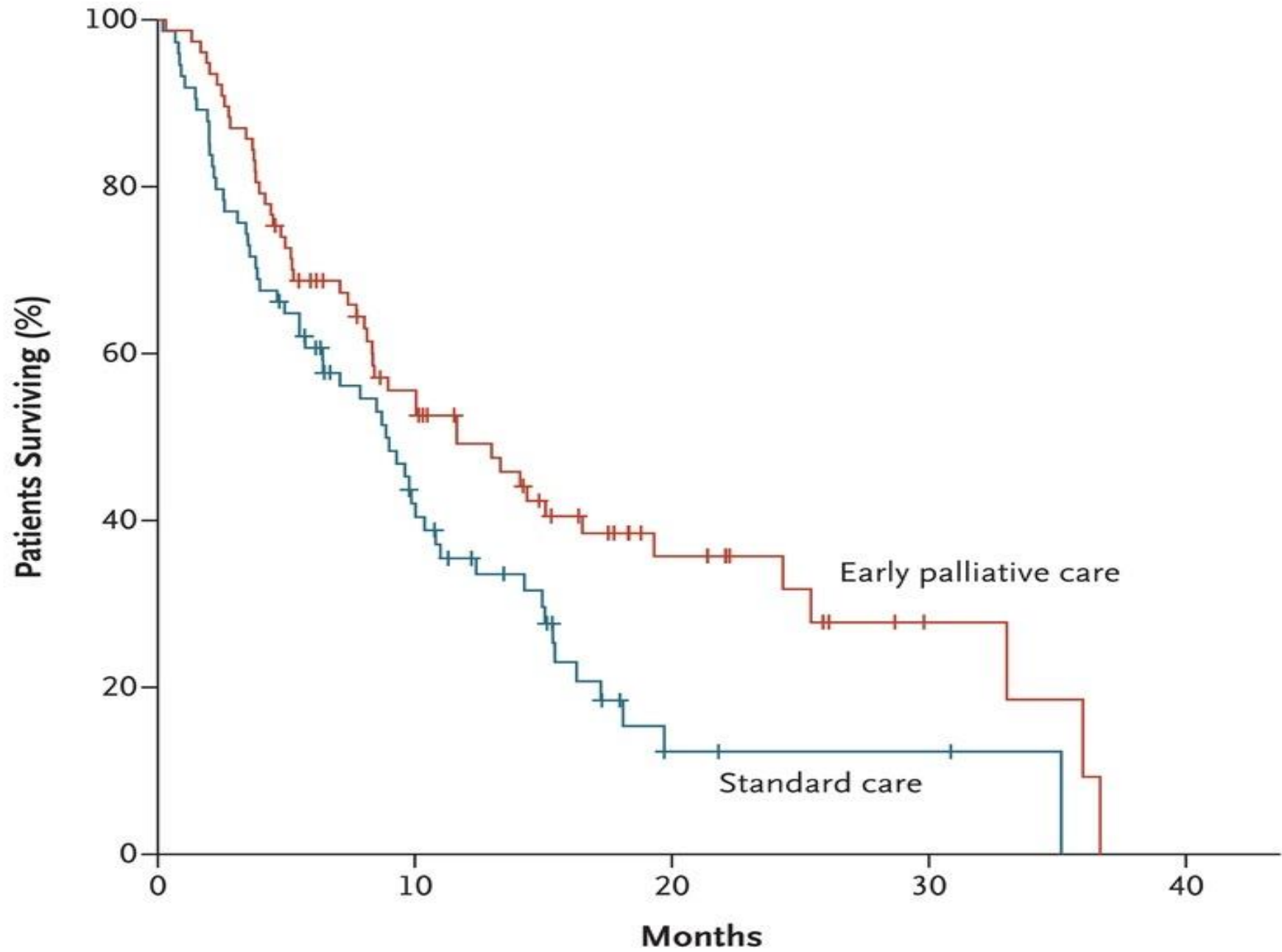
1. **Specialized care for people with a serious illness.**
2. **Assist with symptoms affecting quality of life**
3. **Provided by a specially-trained team working with a provider to offer an extra layer of support**
4. **Appropriate at any age**
5. **Appropriate at any stage of serious illness**
6. **Can be provided along with curative treatment**



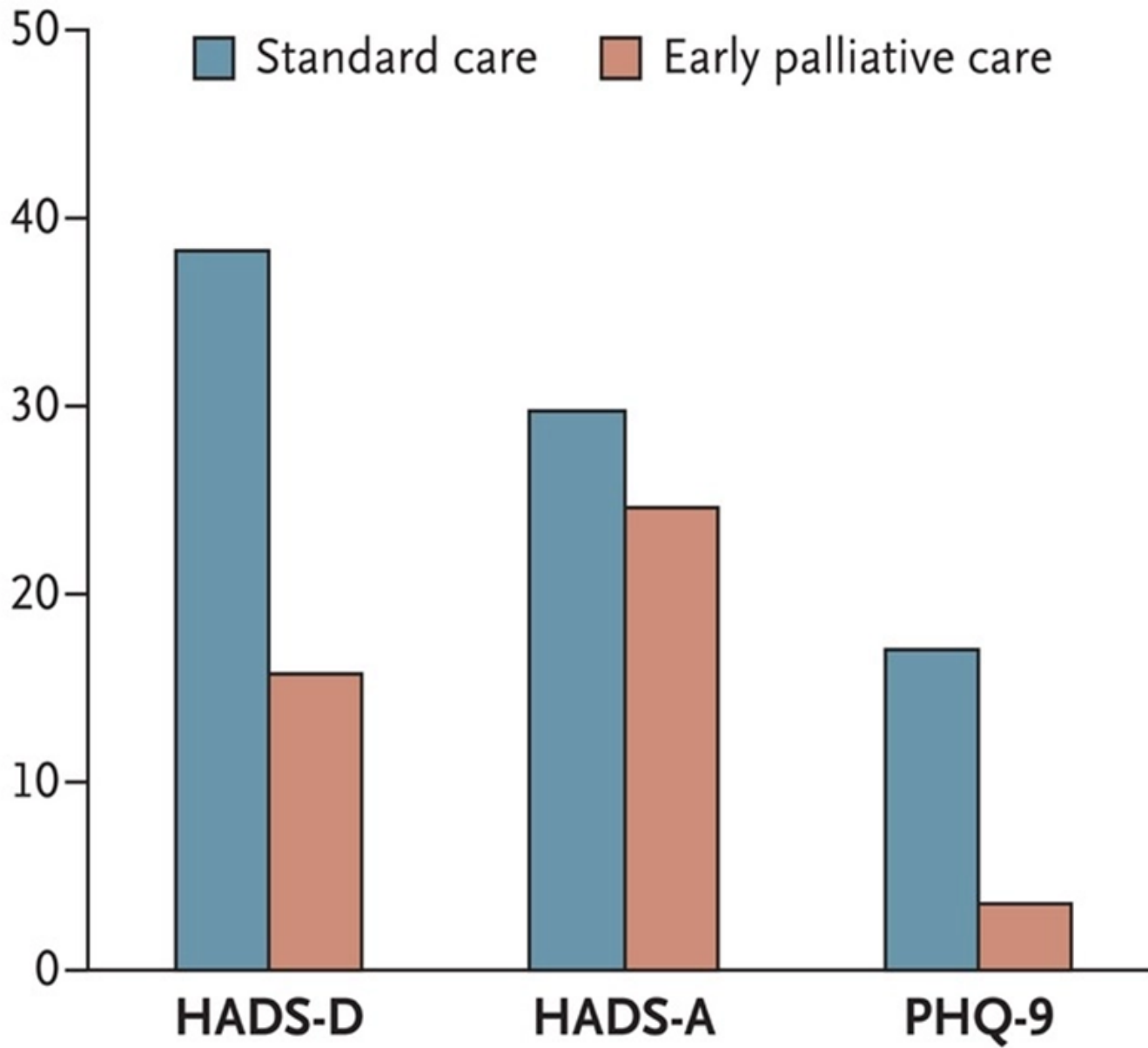
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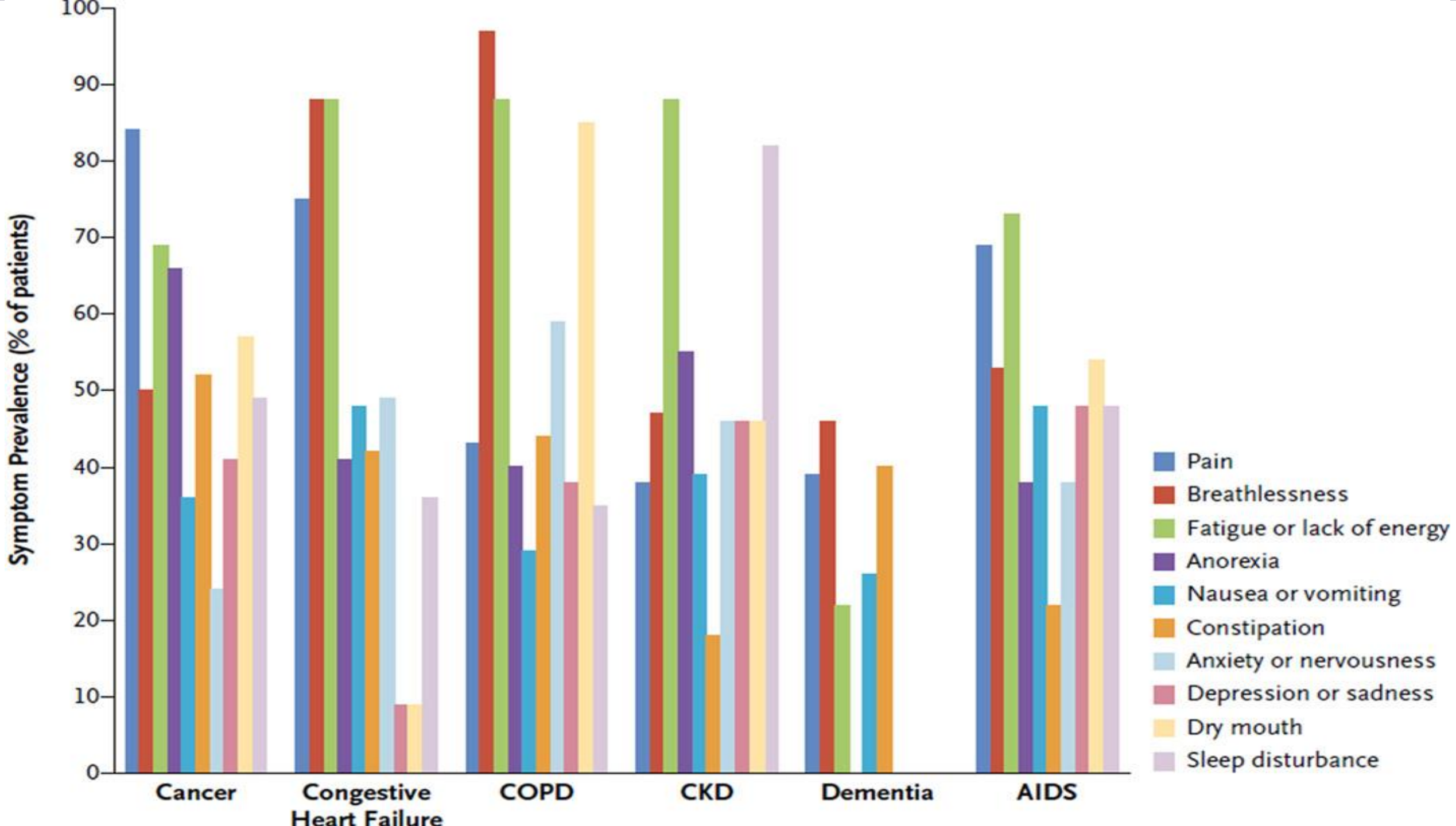
Lynn, J. (2005). "Living long in fragile health: The new demographics shape end of life care."

Hastings Cent Rep Spec No: S14-18.



Patients with Mood Symptoms (%)





Hospice versus Palliative Care

1. Focus on comfort care
2. Does not include curative or life prolonging measures
3. Life limiting illness with end of life within 6 month prognosis
4. Care can be given in the home, relies on hospice, family, friends to deliver care.
5. Bereavement support

1. Focus on comfort care
2. Curative or life prolonging
3. No time restrictions
4. Do not have to be terminal
5. Care teams oversee care: social worker, spiritual support, physician, nurse practitioner
6. Administered anywhere
7. Bereavement support

Indication for referral to Palliative Care

1. **Complex symptom management ie: nausea, pain, dyspnea, anxiety**
2. **Complex medical decisions especially use of life sustaining treatments**
3. **Counseling/support for complex family dynamics**
4. **Care planning for end of life and serious illness**

How to approach patient/families when referring to palliative care.

Language:

- “These providers will work with me to explore distressing symptoms and effective treatments”
- “This team can help you identify what matters most to you and your family and how that fits in your care plan”
- “Palliative care is appropriate at any stage of illness whether we are aiming for cure or life prolonging therapy”

4 Methods to use in difficult conversations about goals of care.

1. Introduction

- 1. Take a few minutes to introduce everyone present. Be clear on interpersonal relationships.**
- 2. Review the purpose of the meeting in clear, direct language.**
- 3. Ensure patient feels prepared to discuss topics (even if this was previously clarified)**

2. Determine what is already known by patient/family

- 1. “Tell me what the doctors have told you”**
- 2. “What is your sense about how things are going”**
- 3. “What changes have you noticed over the last 3-6 months in regards to your health and quality of life”**

4 Methods to use in difficult conversations about goals of care, cont.

1. Medical review

- **Provide update, now that you have an picture of what is understood by patient and family.**
- **Avoid medical jargon “the creatinine is improving but there is a new pleural effusion”**
- **Focus on important and bottom line statement: “getting worse”, “not going to improve”. If appropriate using the word “dying” with compassion**

2. Silence - Allow patient and family to respond once you have given information



VIDEO

Atul Gawande

4 questions to explore with every patient nearing end of life

- What do you understand about your prognosis?
- What are your biggest worries?
- What are your hopes and goals?
- What are the trade offs you are willing to make for the possibility of more time?

It's a process, not an epiphany. It's a series of conversations.

Code status conversations

Use clear and compassionate language

Awareness of setting and it's impact on the decision and retention (ED department vs office visit)

Patient and families are stressed and overwhelmed during many of these conversations

May need multiple conversations about this topic

Code status conversations, cont

Language to Avoid

- **“If there was nothing left to do...”**
- **“If your heart stops beating, do you want us to do nothing?”**

Code status conversations, cont

Assure patients and families there is ALWAYS something the medical team can be doing....the goals may have changed, but care continues.

- Comfort medications
- Emotional support
- Spiritual support
- Simple human presence – You will not be alone through this.

Include language that allows death (a comfortable one to actually be an option).

- If your condition worsens despite these medical treatments, and your heart stops beating or you stop breathing, do you want us to ensure you are comfortable and allow a natural death? Or would you like us to try and restart your heart?

Code status conversations, cont

Some tough responses

“You can restart my heart but I don’t want that breathing machine?”

“Don’t bring me back if I’m going to be a vegetable?”

“You can keep me alive for 3 days but that’s it, then pull the plug”

References

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ADD VIDEO LINK