Keynote presentation

LIVING BEYOND
BREAST CANCER®

Palliative care & symptom management

Improving quality of life in metastatic breast cancer

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Penn Medicine

LIVING WELL WITH METASTATIC BREAST CANCER

The Role of Supportive and Palliative Care

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April 19, 2026

Overview

What are the supportive care needs of people living with metastatic breast cancer?

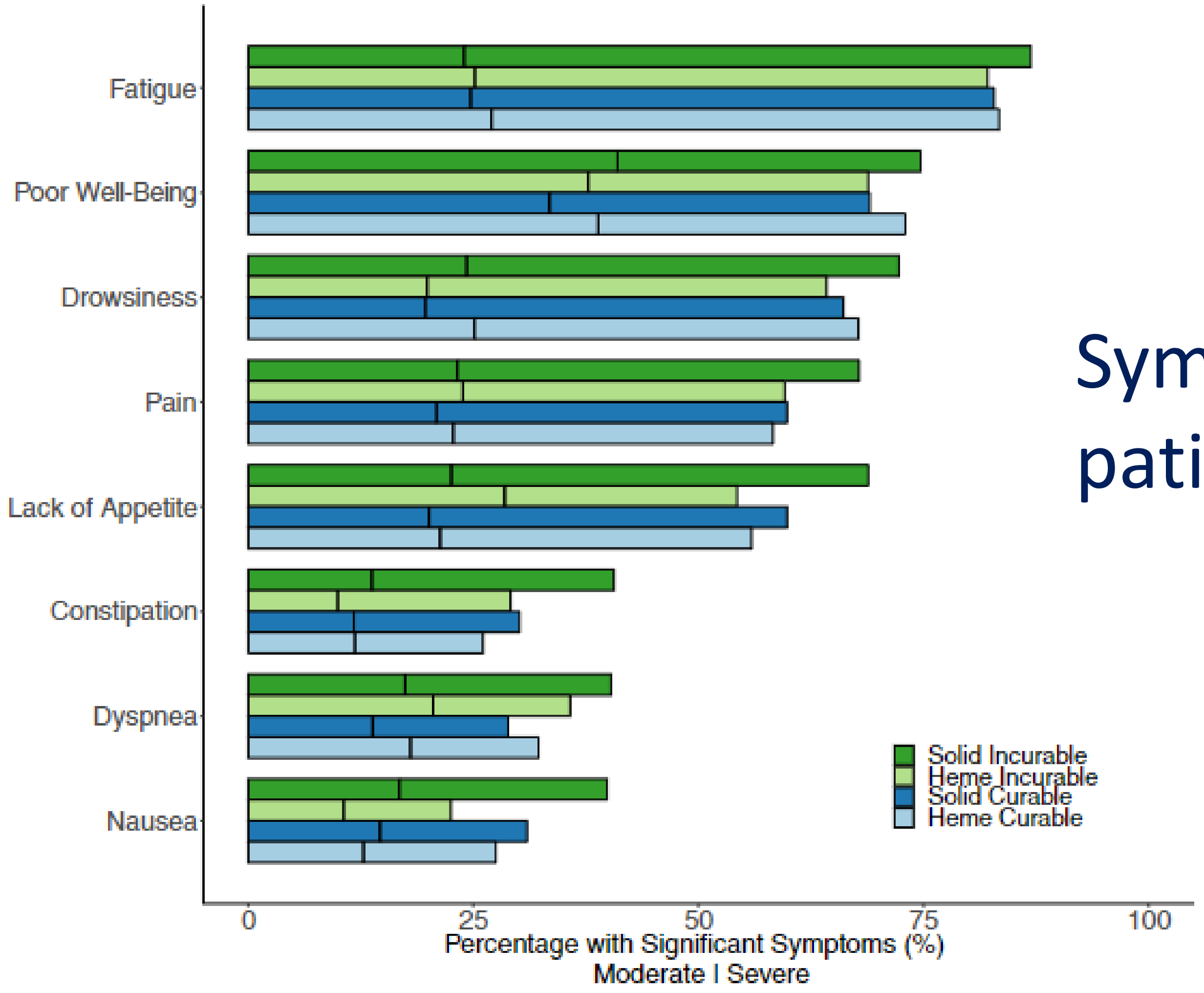
How palliative and supportive care can help people with metastatic breast cancer.

How to access supportive care – even if you are receiving care where there is not a dedicated palliative care team.

Managing side effects to achieve better quality of life – what does that look like?

Some tips for communication and discussing goals and values.

Cancer: symptom burden

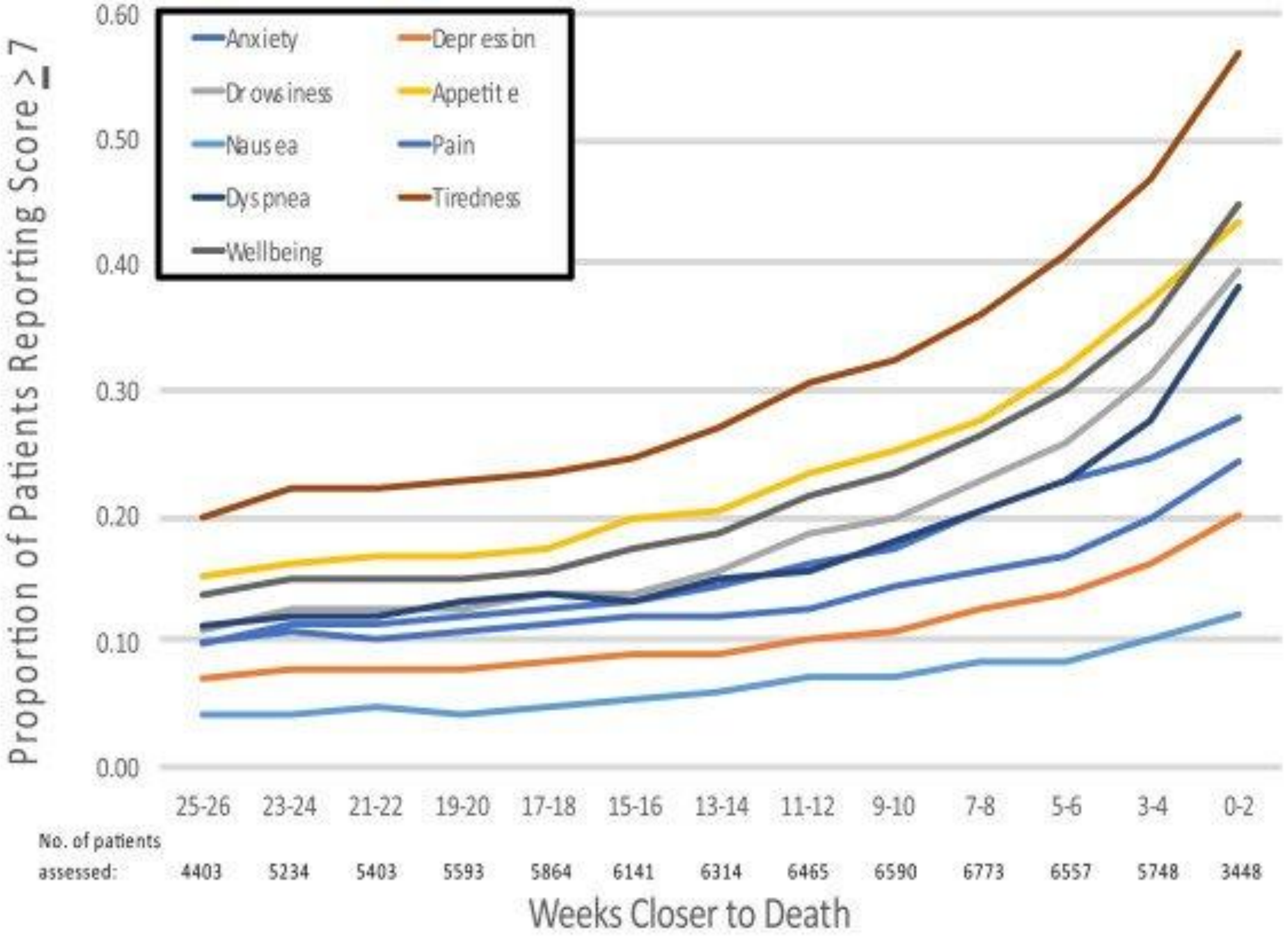


Symptom burden is high among ALL patients with cancer

Newcomb, R.A., Nipp, R.D. et al. Cancer, 126: 2924-2933. https://doi.org/10.1002/cncr.32833

Cancer: symptom burden

Symptom burden worsens at the end of life



Bubis LD, et al. *J Pain Symptom Manage*. 2020;59(1):58-66.e4.

Cancer treatment affects multiple domains of well being

Social

Physical

Emotional

Functional

Treatment side effects are common and impactful

Most patients receiving cancer directed therapy experience at least one side effect

- ~25% report a grade IV side effect[1]
- Acute vs. chronic side effects

How do treatment side effects impact continuation of therapy?

- Aromatase inhibitors
  - Severe joint/bone/muscle symptoms in 1/3 patients
  - Discontinuation in 10-20% patients[2]
- High symptom burden: lower adherence to oral chemotherapies[3]

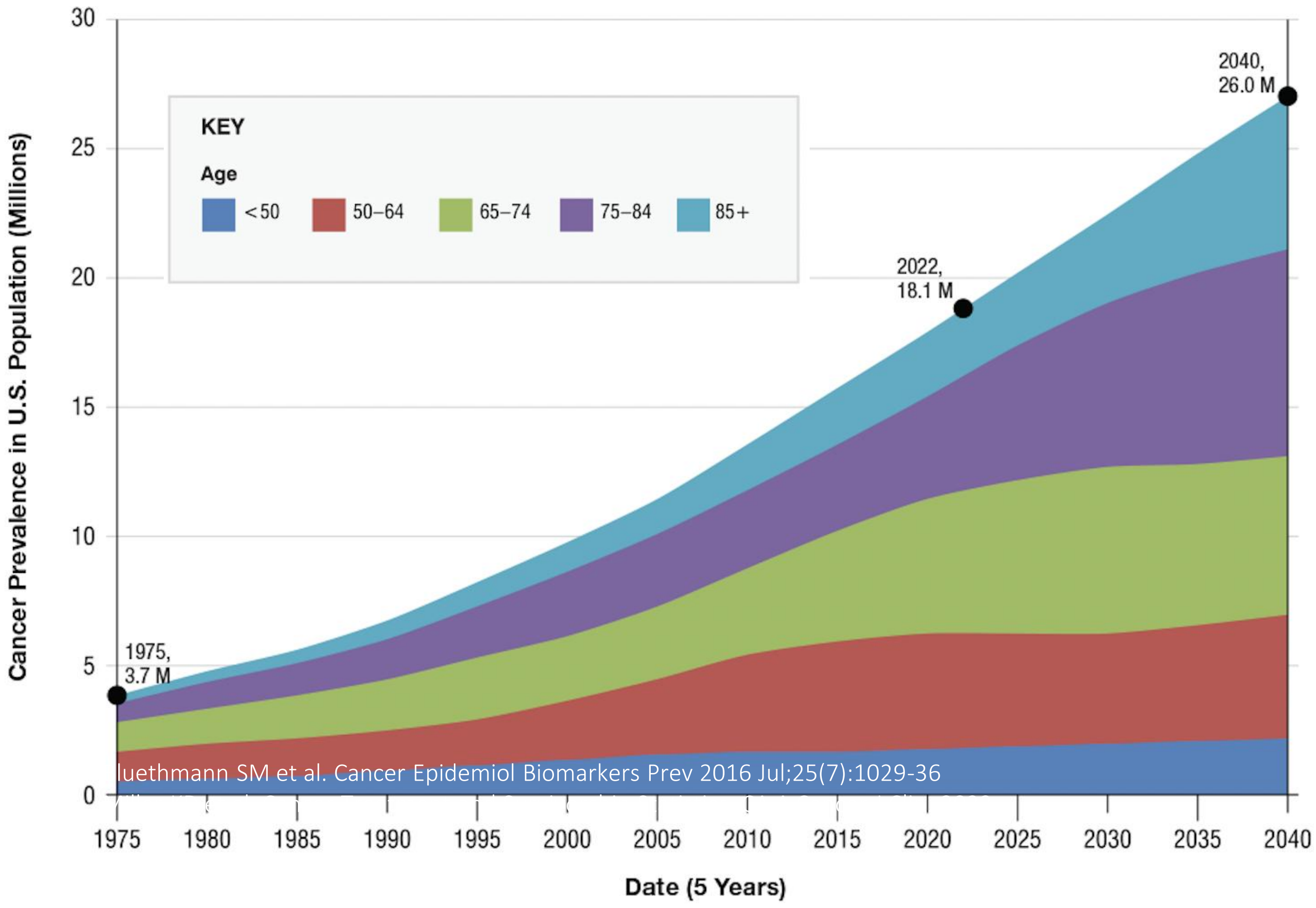
[1] Pearce A et al. PLoS One. 2017; 12(10): e0184360.

[2] Presant CA et al. Clin Breast Cancer. 2007;7(10):775.

[3] Greer et al. J Natl Compr Canc Netw. 2019 Mar 1; 17(3): 221–228.

More Americans are living with cancer and treatment symptoms

Cancer Prevalence and Projections in U.S. Population from 1975–2040

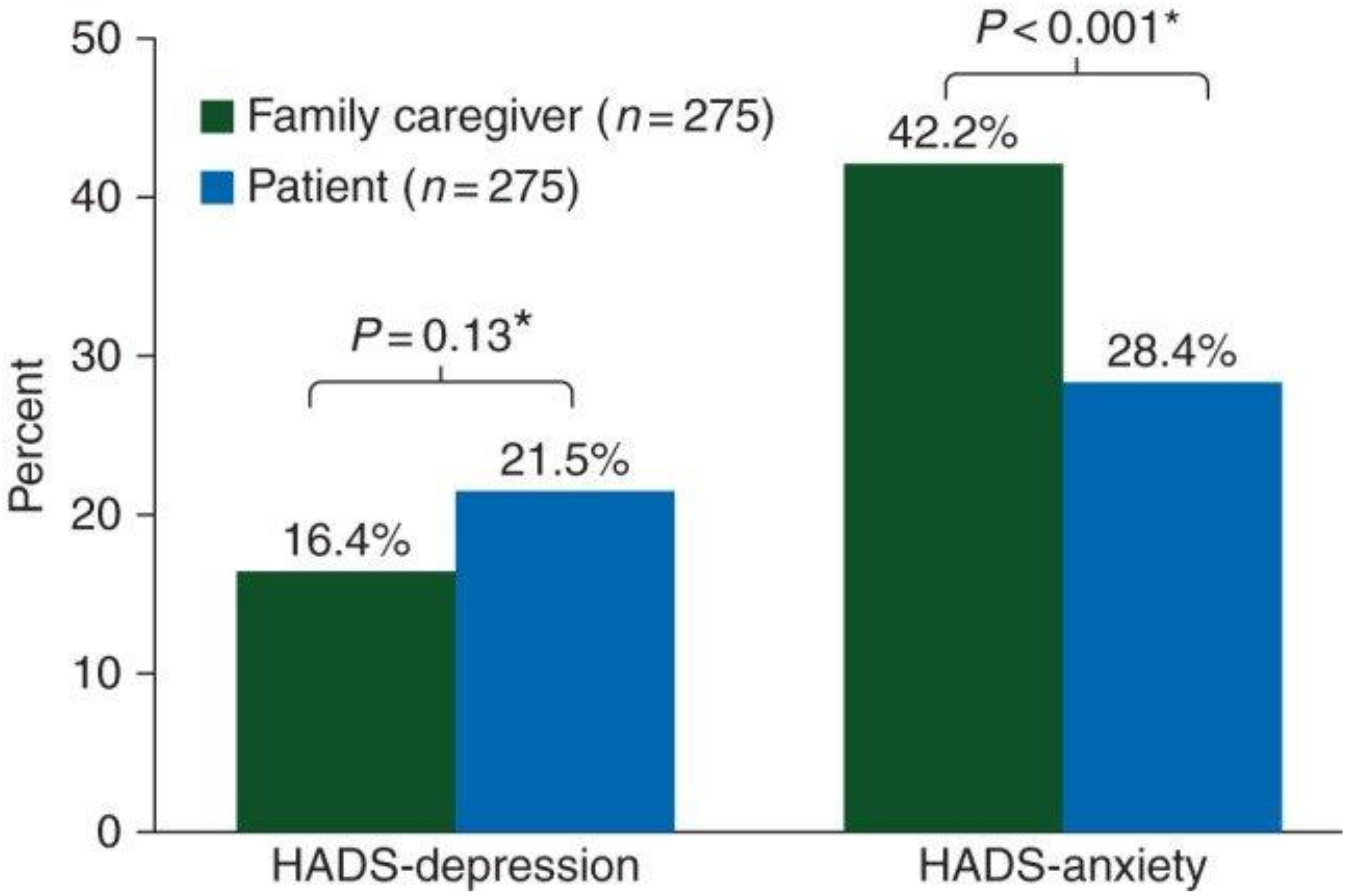


luethmann SM et al. Cancer Epidemiol Biomarkers Prev 2016 Jul;25(7):1029-36

- 2/3 of survivors are currently age 65 or older.
- By 2040, 74% of cancer survivors in the United States will be age 65 or older.

https://cancercontrol.cancer.gov/ocs/statistics

High Caregiver Distress



Anxiety and depression are **prevalent** among family caregivers

-

Nipp RD, et al. *Ann Oncol*. 2016;27(8):1607-12.

Supportive care can help

- Management of adverse effects of disease and treatment
- Encompasses the entire trajectory of illness
- Emphasis on patient and family
- Integration of many clinical specialties

- Synonym: **palliative care**

What is Palliative Care?

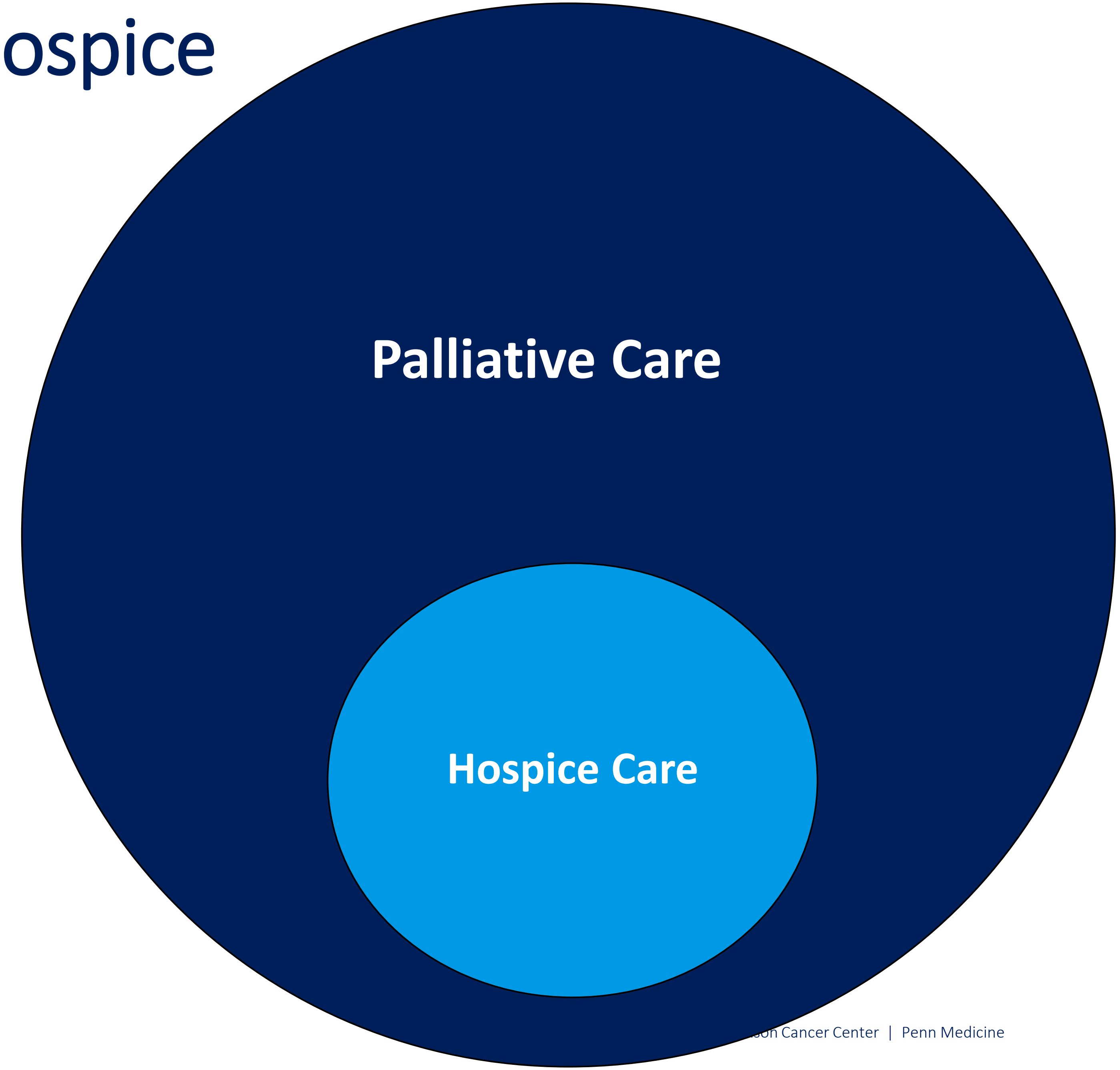
- Specialized medical care for people with **serious illness.**
- Focuses on providing patients with **relief** from the symptoms, pain, and stress of a serious illness
- The goal is to **improve quality of life** for both the patient and the family.
- Appropriate at any age and point in the disease and **is provided along with regular disease treatment.**

Myth: Palliative care = hospice

TRUTH: HOSPICE IS ONE TYPE OF PALLIATIVE CARE

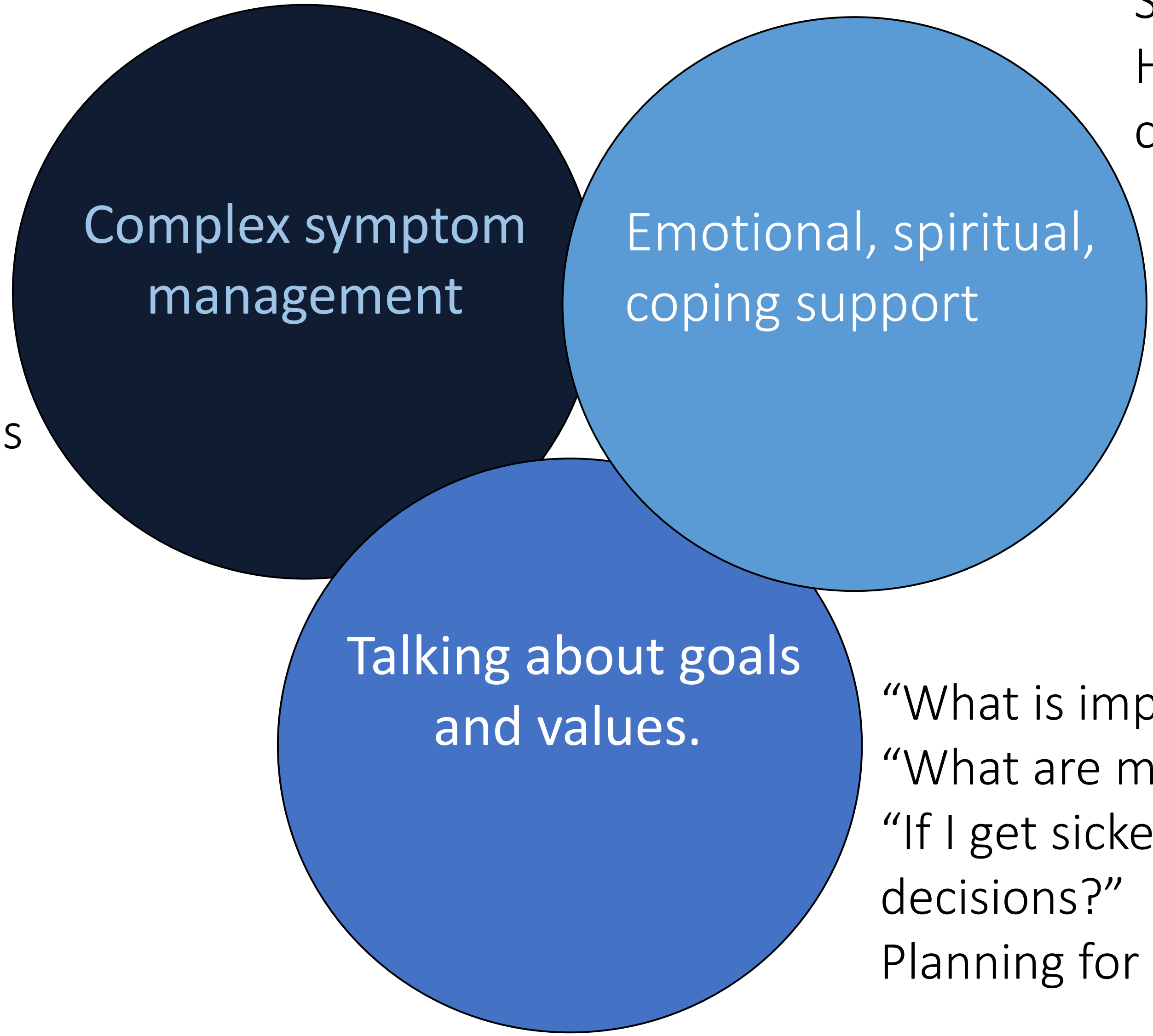
TRUTH: MOST PALLIATIVE CARE IS PROVIDED TO PATIENTS RECEIVING DISEASE-DIRECTED THERAPIES

TRUTH: YOU DO NOT HAVE TO BE AT THE END OF LIFE TO RECEIVE PALLIATIVE CARE



Palliative care in Oncology

Pain
Shortness of breath
Nausea/vomiting
Mood
Sleep
Fatigue
Appetite and weight loss
Sexual side effects



Complex symptom management

Emotional, spiritual, coping support

Talking about goals and values.

Supporting families
Helping parents with cancer cope

"What is important to me?"
"What are my goals?"
"If I get sicker, who can help with medical decisions?"
Planning for the future

Who provides supportive care?

- **Medical oncology teams**
  - Symptom management
  - Coping support
  - Help with difficult medical decisions
- Nursing
- Social work
- PT/OT/Speech therapy
- Mental Health
- Nutrition
- Home care
- Cancer rehab
- Interventional services (pulmonary, radiology)

Who provides palliative care?

- **Specialty palliative care** is a team effort!
- **Interdisciplinary/multidisciplinary**
  - Nurses (RNs)
  - Nurse practitioners (NPs) and physician assistants (PAs)
  - Physicians (MDs)
  - Social workers (SWs)
  - Chaplains + spiritual care providers
  - Psychologists
  - Pharmacists
  - Grief/bereavement counselors
  - Others – art/music therapists, volunteers

Who provides palliative care for oncology patients?

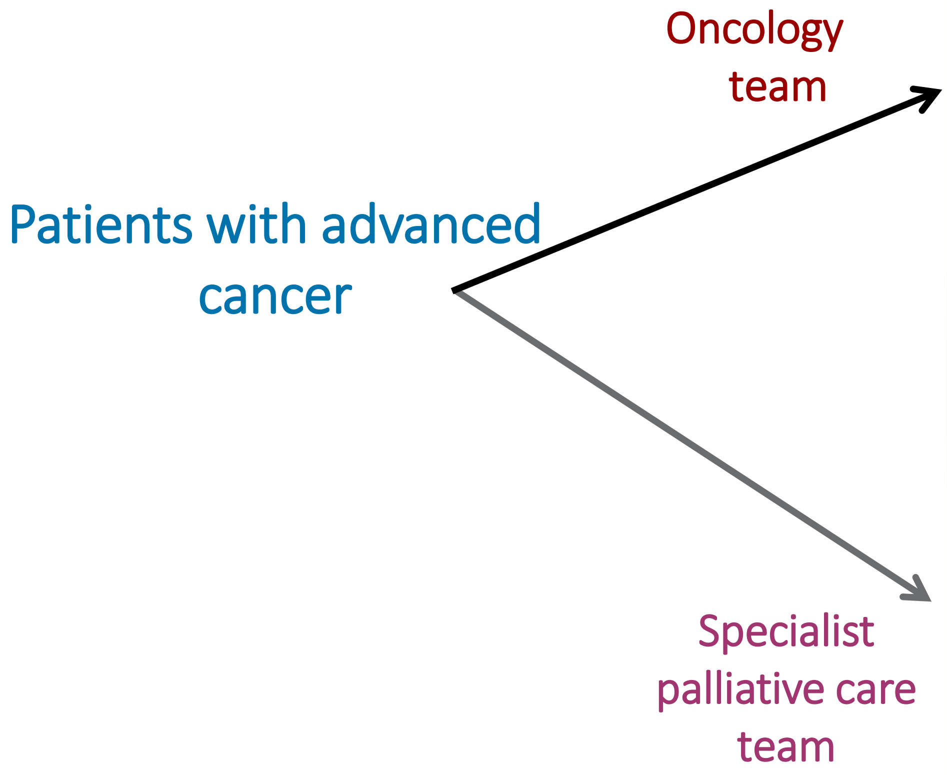
Common misconception: only palliative care trained specialists can provide palliative care

For patients with advanced cancer, their oncology teams provide

- Pain and symptom management
- Psychosocial support
- Goals and values-based discussions
- Assistance with medical decision-making

Primary palliative care = generalist palliative care = supportive care

Who provides palliative care for oncology patients?


Patients with advanced cancer

Oncology team

Specialist palliative care team


Representative Skill Sets for Primary and Specialty Palliative Care.

Primary Palliative Care

- Basic management of pain and symptoms
- Basic management of depression and anxiety
- Basic discussions about
  - Prognosis
  - Goals of treatment
  - Suffering
  - Code status

Specialty Palliative Care

- Management of refractory pain or other symptoms
- Management of more complex depression, anxiety, grief, and existential distress
- Assistance with conflict resolution regarding goals or methods of treatment
  - Within families
  - Between staff and families
  - Among treatment teams
- Assistance in addressing cases of near futility

Quill TE and Abernethy AA. N Engl J Med 368; 13.

Where can I get palliative care?

Palliative/Supportive Care in Serious Illness

CHALLENGES: AVAILABILITY AND ACCESS

Specialty Palliative Care Team Availability

Specialty palliative care teams are reported in

83.6%

of all U.S. acute care hospitals with more than 50 beds, but variation is significant.

Figure 2: Hospital Palliative Care Prevalence by Bed Size and Tax Status

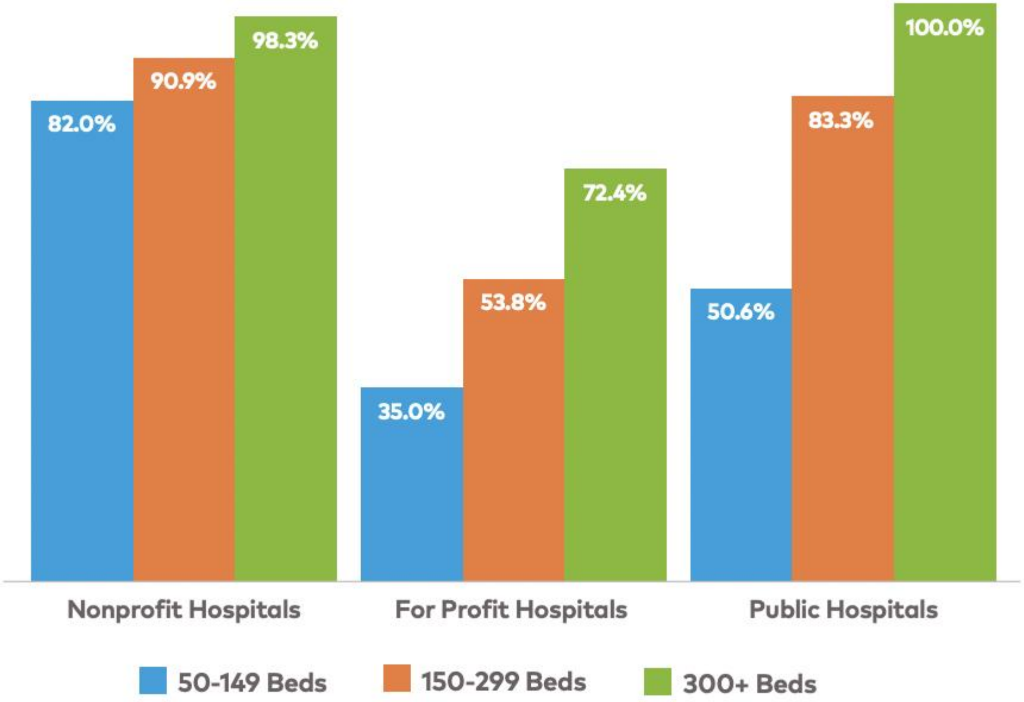
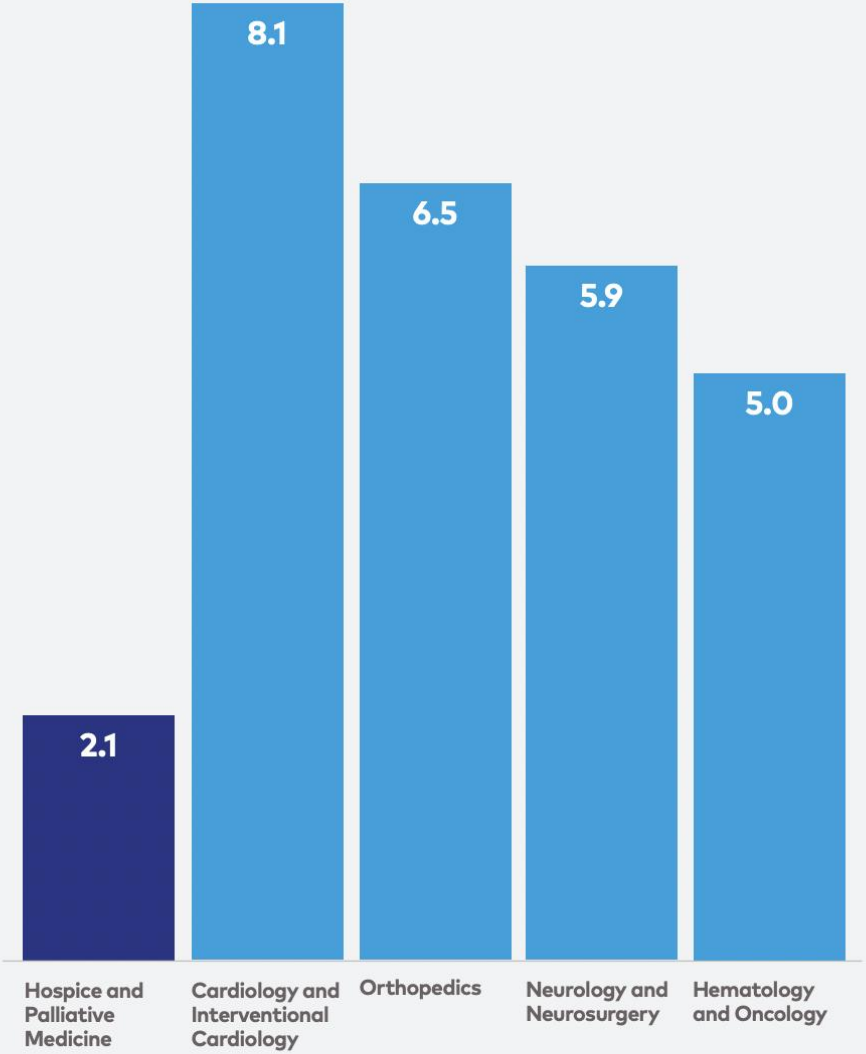


Figure 4: Selected Physician (MD) Specialties per 100,000 U.S. Population



Cost and coverage considerations

PRACTICAL TIPS

Most insurance plans will cover outpatient palliative care services

Common to have a specialty visit co-pay as you would with dermatology or endocrinology.

Ask about cost/coverage concerns early on (at the time of referral) so you are not surprised by a co-pay or co-insurance.

Easing the financial burden: telehealth/telemedicine visits can reduce travel (tolls, gas, parking) and time off work

What happens during a palliative care visit?

Getting to know patients and families

Detailed symptom and medication review

Medication and non-medication suggestions

Talking about coping with cancer

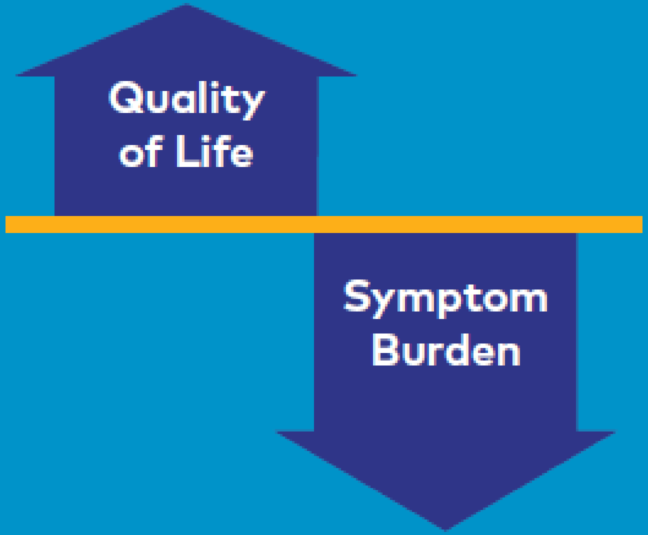
Referral to coping support experts

Other referrals: PT/OT, nutrition, interventional procedures

Coordination of care with oncology

Palliative Care Drives a Positive Patient Experience

IMPROVES QUALITY OF LIFE AND SYMPTOM BURDEN



Reduces symptom distress by

66%

with improvements lasting months after initial consultation[1]

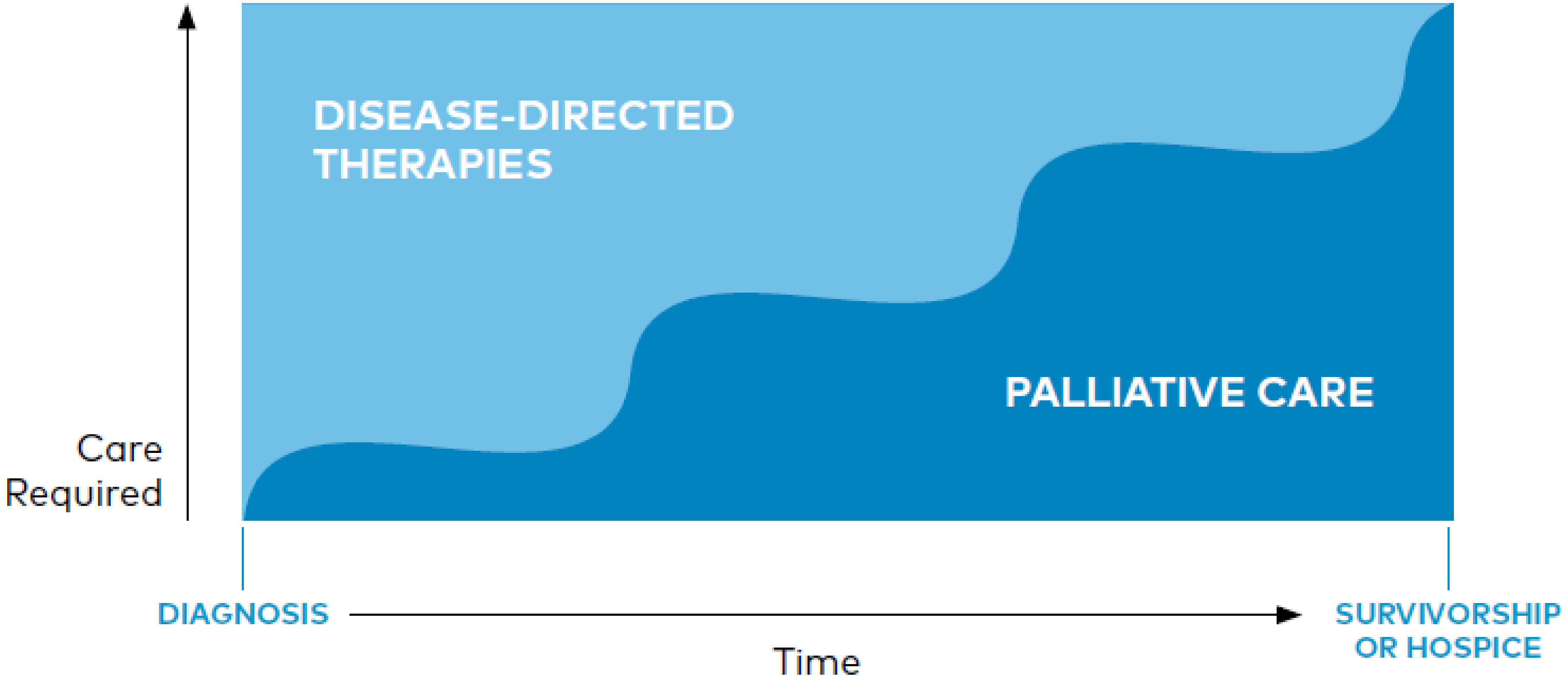
DRIVES HIGH SATISFACTION AND POSITIVE PATIENT EXPERIENCES

93%

of people who received palliative care are likely to recommend it to others[2]

https://www.capc.org/

Palliative Care is Delivered Alongside Cancer Treatment



Core competencies in palliative care – – – →

Specialty palliative care – – – →

https://www.capc.org/

What if my health system, hospital, or clinic does not have palliative care?

WAYS TO GET THE SUPPORT YOU NEED

Supportive care can be delivered alongside oncology care

- Ask about a dedicated “symptom management” visit or telehealth visit
- Make a list of symptoms/issues affecting your quality of life
- Write down 1-2 quality of life goals and share them with your oncology team
- Share upcoming events/milestones with your team
- Track symptoms between visits

What if my health system, hospital, or clinic does not have palliative care?

WAYS TO GET THE SUPPORT YOU NEED

Ask about referrals to:

- Pain management
- PT/OT
- Cancer rehab or physiatry
- Nutrition
- Counseling/mental health care
- Spiritual care
- Integrative/complementary medicine
  - Reiki, acupuncture, massage

What questions should I be asking?

QUESTIONS THAT CAN HELP PRIORITIZE YOUR QUALITY OF LIFE

- What are my options for managing this symptom?
- What tradeoffs should I know about?
- How will this affect my daily life?
- What support is available outside of treatment?

Managing side effects: a real life example

Kim is a 58 year old with ER+, HER2- breast cancer with bone and liver metastases who had initially been diagnosed with localized breast cancer 8 years ago. She had surgery, radiation, and adjuvant endocrine therapy. 5 months ago, she developed back pain and imaging showed disease in her lumbar spine and sacrum, and several liver lesions. One of the liver lesions was biopsied, and pathology showed metastatic breast cancer, again ER+, HER2-.

She started on letrozole and abemaciclib about 4 months ago. She also received 5 fractions of radiation to the lower spine. She had scans one month ago which showed that her bone lesions had stabilized and that the disease in the liver decreased in size.

At her routine oncology visit, she is referred to palliative care as she shares with her oncology NP that she is struggling with fatigue, diarrhea, joint pain, and low mood.

Palliative care visit

GETTING TO KNOW KIM

Kim presents for her new patient palliative care visit with her daughter Anne, who is a nurse.

Palliative care review:

- Fatigue: used to walk 3x/week with her friends, Pilates once a week. No longer able to go for long walks.
- Joint pain: since staring letrozole, feels “100 years old,” affecting wrists, knees, ankles, hips. Told not to take Advil every day
- Diarrhea: since starting abemaciclib, 3-4 loose bowel movements a day
- Low mood: shared that she is wondering if this is her “new normal,” not sure who she is anymore. Used to work full time, host book club, misses seeing friends.

Supportive care interventions

BUILDING RAPPORT, SYMPTOM MANAGEMENT, COPING SUPPORT

Fatigue: discussed energy conservation, smaller bursts of activity with frequent rest periods, exercise plan (5-10 minutes of walking, add 5 min each week), referral to PT

Joint pain: trial of celecoxib, diclofenac gel topically, referral for aquatherapy (PT)

Diarrhea: clear instructions on diarrhea management (loperamide as needed) written out and reviewed with Kim and Anne.

Mood/coping: talked about her goals/hopes (to get back to work part time, hosting book club, being more present with family so she can enjoy her grandkids). Referred to palliative care social worker for counseling.

Follow up

Kim returns for a palliative care visit 4 weeks later on her own.

Fatigue: walking 20 minutes three times a week with her neighbor, has had 3 aquatherapy sessions, energy level better, had lunch with her book club

Joint pain: has been taking celecoxib most days and diclofenac gel

Diarrhea: well controlled with loperamide 2-3x/day, takes it 3 days a week on average

Mood: met with palliative care social work for counseling, attended a support group, has started doing some journaling. Still some days when mood is low, worrying about the future. Thinking about the "what-ifs."

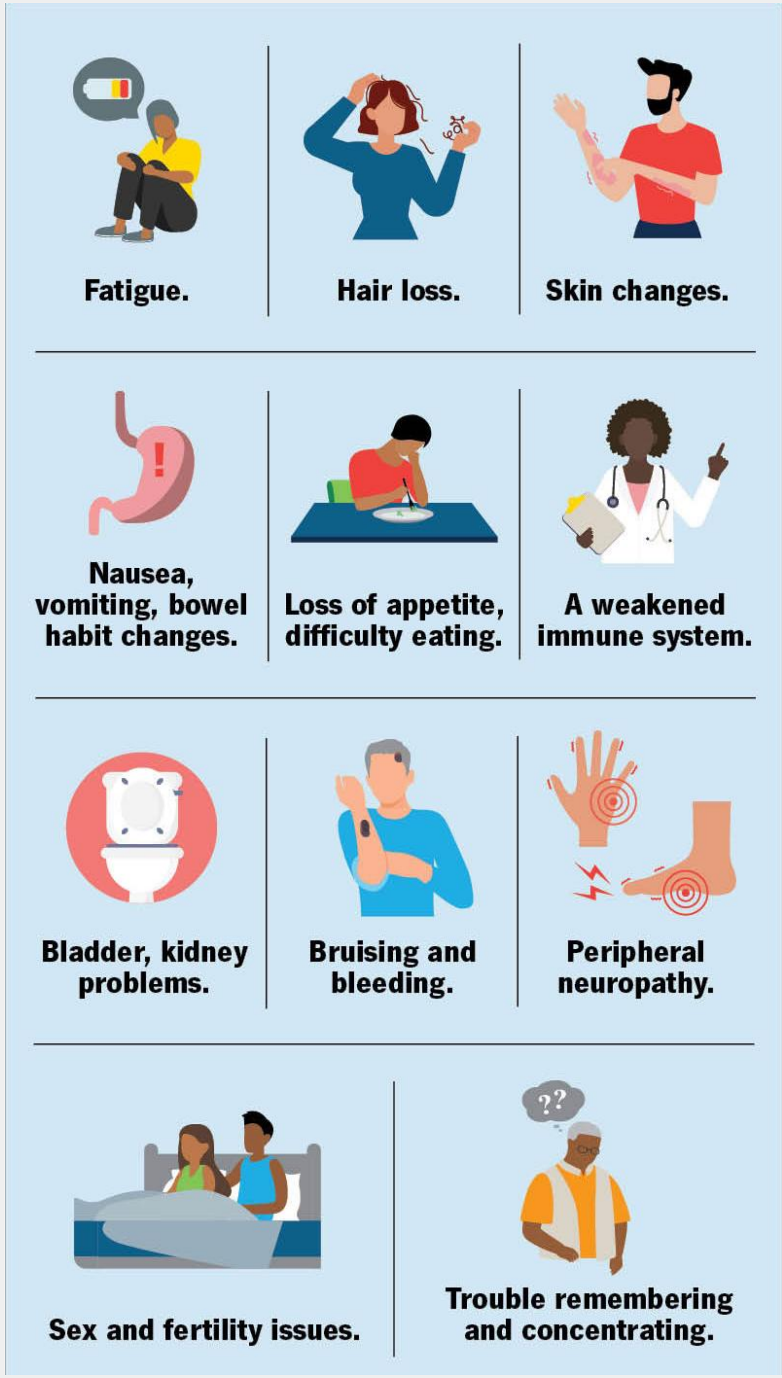
Plan for next visit: spend some time exploring her goals/values for future care, what she would want to prioritize if she gets sicker. She will bring her husband and daughter back for that visit.

Side effect management matters

QUALITY OF LIFE IS AN IMPORTANT CANCER OUTCOME!

- Side effects are not just “a part of treatment”

- High symptom burden → poor quality of life → complicates further treatment



Supportive care is good cancer care

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