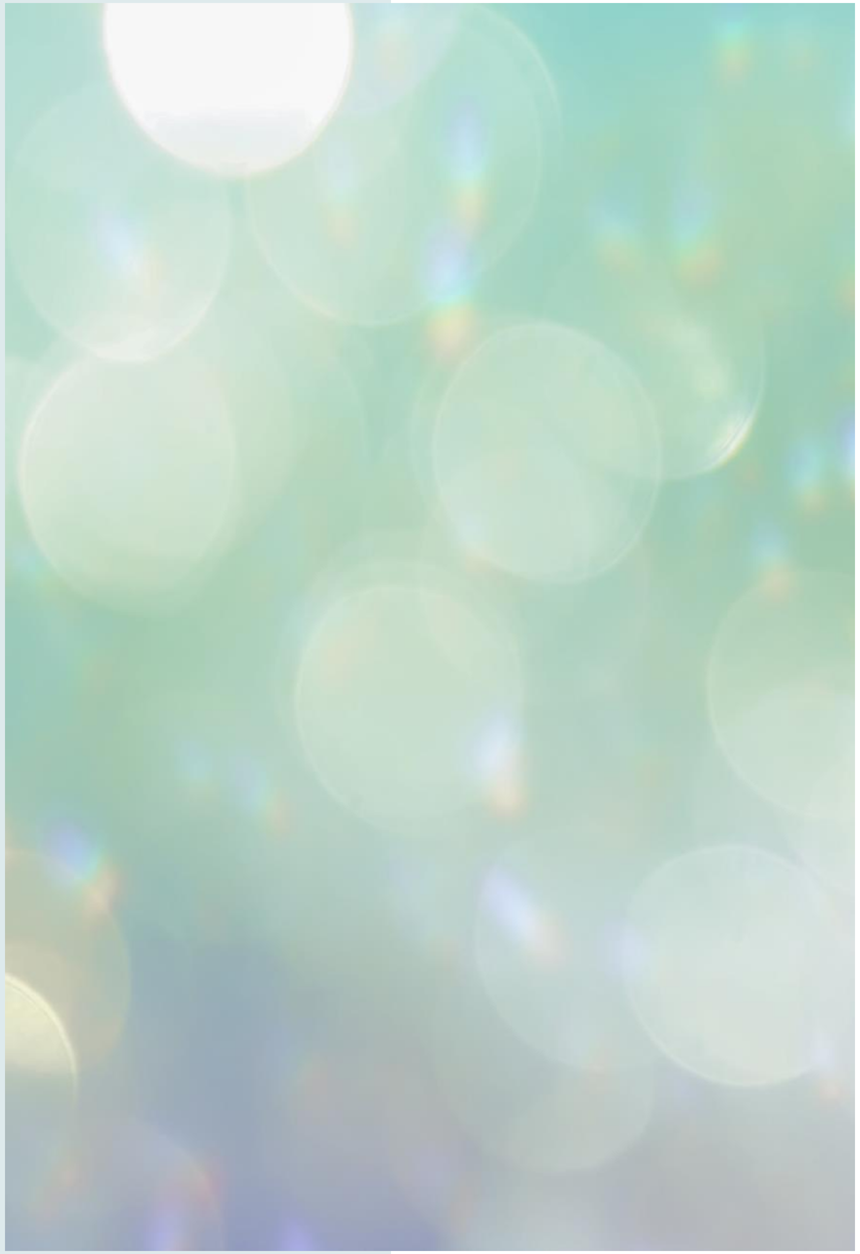
BARRIERS TO SERIOUS ILLNESS CARE IN THE PRIMARY CARE SPACE

How can palliative medicine help?

Eda Selin Turgut, DO
Hospice & Palliative Medicine
VCU Health



OBJECTIVES

1. Identify challenges faced by primary care physicians to deliver high quality primary palliative care.
2. Review social determinants of health and identify resources and initiatives that can help support providers.
3. Explore palliative care referral criteria from the primary care space.
4. Discuss areas to improve interprofessional working relationships to continue to promote health and wellness of the whole patient.
5. Comment on strategies that can be employed by palliative care to support continued education and skill development of primary palliative care.

CASE: MRS. M.

68-year-old female

- Hypertension, diabetes, GERD, bilateral chronic knee pain, and anxiety
- **Today's vitals: T 36.8 deg C, HR 91, BP 158/90, RR 16, Weight 180# (up 10 lbs from last visit)**

Missed and re-scheduled her last two visits

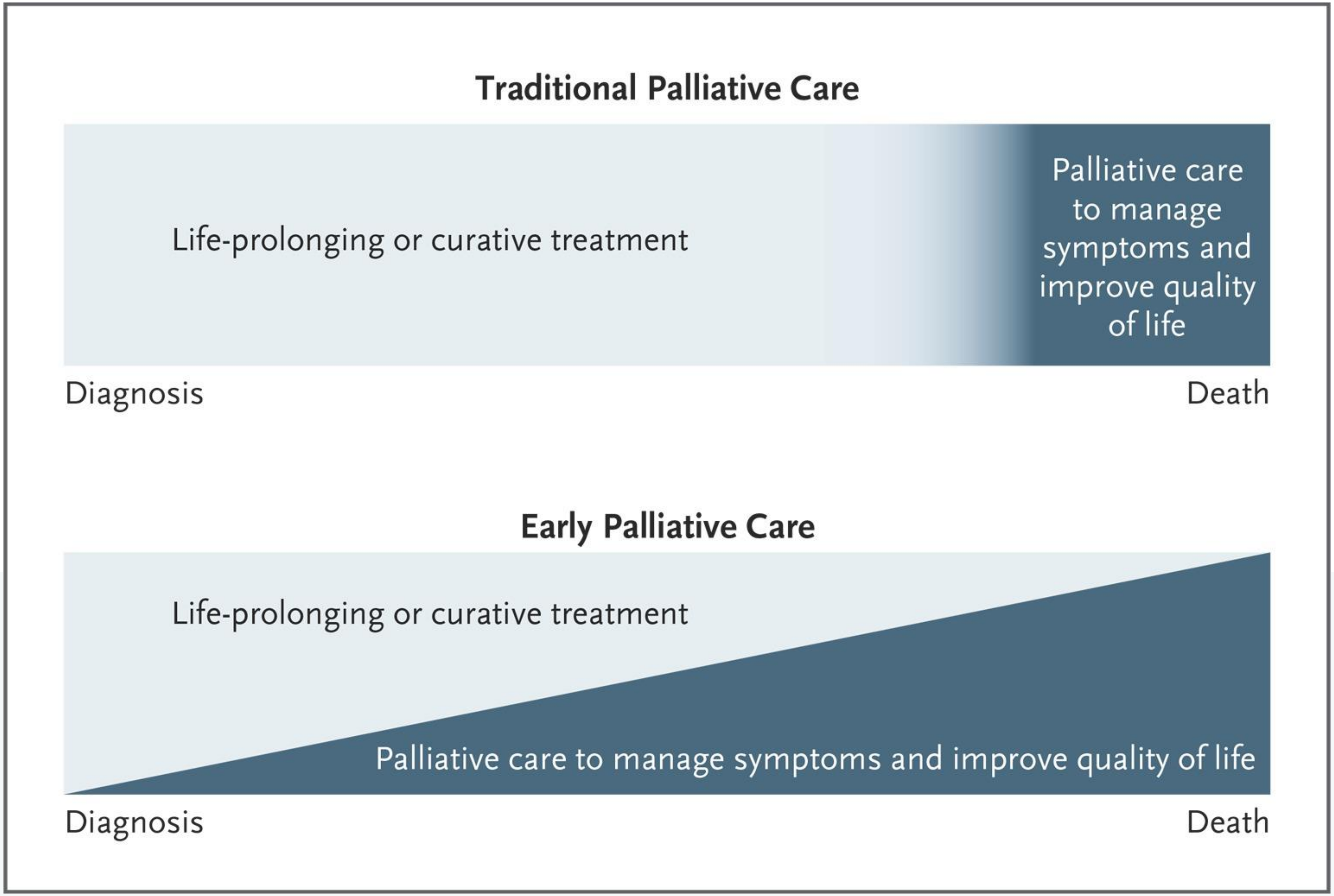
- **Overdue** for screening mammogram, labs 8 months old
- Out of medications for 3 weeks

Questions for patient

- Why is Mrs. M missing follow-ups?
- Why didn't she contact office for refills?

Characteristics shared by Primary and Palliative care

- Treat the whole person, not just the disease
- Physical, psychological, social and spiritual issues as well as relationships (family and community) impact health and overall well-being
- Both act as educators, counselors, and advocates for their patients and their families



Traditional Palliative Care

Life-prolonging or curative treatment

Palliative care to manage symptoms and improve quality of life

Diagnosis

Death

Early Palliative Care

Life-prolonging or curative treatment

Palliative care to manage symptoms and improve quality of life

Diagnosis

Death

SUPPORT FOR EARLY PALLIATIVE INTERVENTION

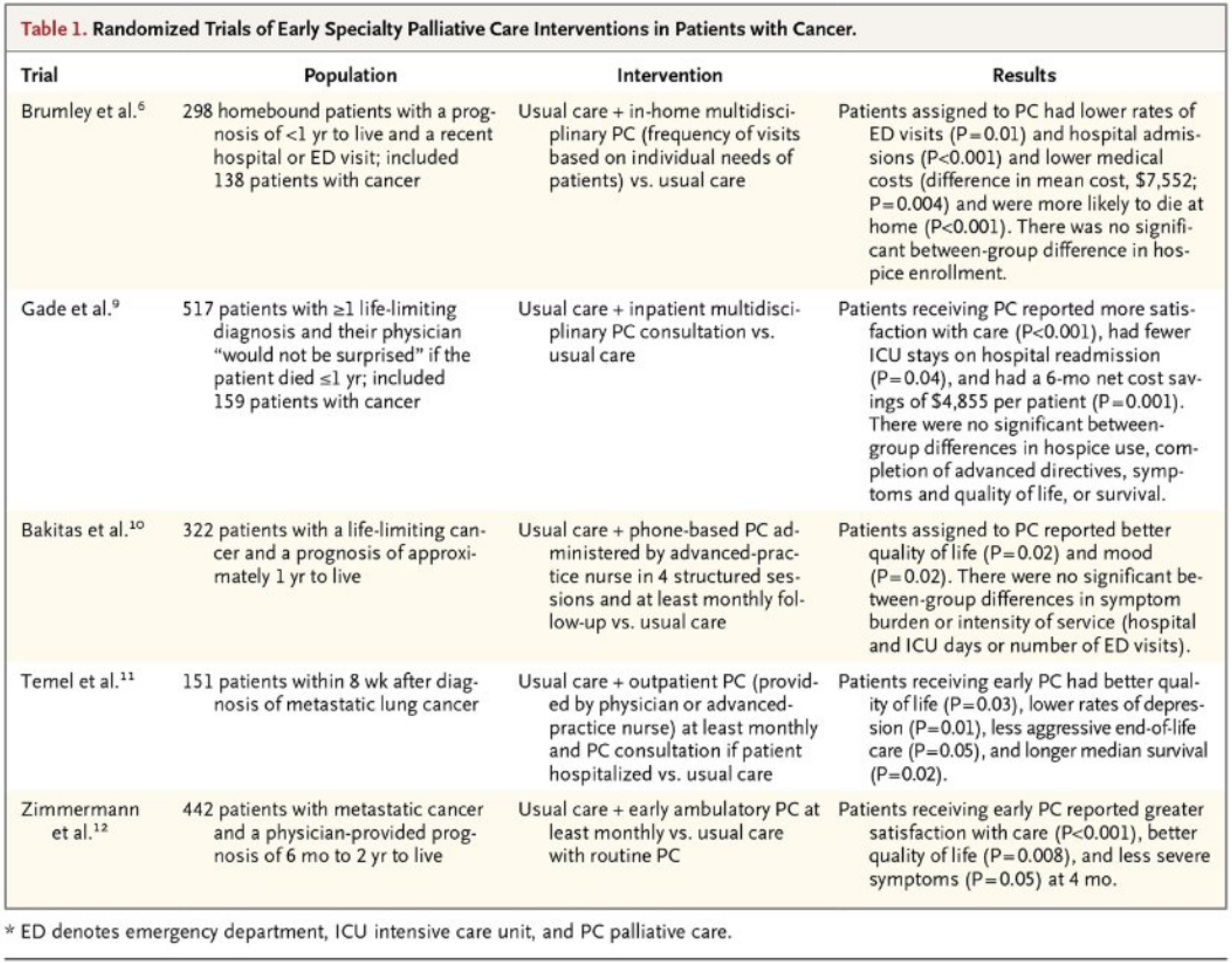


Table 1. **Randomized Trials of Early Specialty Palliative Care Interventions in Patients with Cancer.**

Trial	Population	Intervention	Results
Brumley et al.[6]	298 homebound patients with a prognosis of <1 yr to live and a recent hospital or ED visit; included 138 patients with cancer	Usual care + in-home multidisciplinary PC (frequency of visits based on individual needs of patients) vs. usual care	Patients assigned to PC had lower rates of ED visits (P=0.01) and hospital admissions (P<0.001) and lower medical costs (difference in mean cost, $7,552; P=0.004) and were more likely to die at home (P<0.001). There was no significant between-group difference in hospice enrollment.
Gade et al.[9]	517 patients with ≥1 life-limiting diagnosis and their physician "would not be surprised" if the patient died ≤1 yr; included 159 patients with cancer	Usual care + inpatient multidisciplinary PC consultation vs. usual care	Patients receiving PC reported more satisfaction with care (P<0.001), had fewer ICU stays on hospital readmission (P=0.04), and had a 6-mo net cost savings of $4,855 per patient (P=0.001). There were no significant between-group differences in hospice use, completion of advanced directives, symptoms and quality of life, or survival.
Bakitas et al.[10]	322 patients with a life-limiting cancer and a prognosis of approximately 1 yr to live	Usual care + phone-based PC administered by advanced-practice nurse in 4 structured sessions and at least monthly follow-up vs. usual care	Patients assigned to PC reported better quality of life (P=0.02) and mood (P=0.02). There were no significant between-group differences in symptom burden or intensity of service (hospital and ICU days or number of ED visits).
Temel et al.[11]	151 patients within 8 wk after diagnosis of metastatic lung cancer	Usual care + outpatient PC (provided by physician or advanced-practice nurse) at least monthly and PC consultation if patient hospitalized vs. usual care	Patients receiving early PC had better quality of life (P=0.03), lower rates of depression (P=0.01), less aggressive end-of-life care (P=0.05), and longer median survival (P=0.02).
Zimmermann et al.[12]	442 patients with metastatic cancer and a physician-provided prognosis of 6 mo to 2 yr to live	Usual care + early ambulatory PC at least monthly vs. usual care with routine PC	Patients receiving early PC reported greater satisfaction with care (P<0.001), better quality of life (P=0.008), and less severe symptoms (P=0.05) at 4 mo.

* ED denotes emergency department, ICU intensive care unit, and PC palliative care.

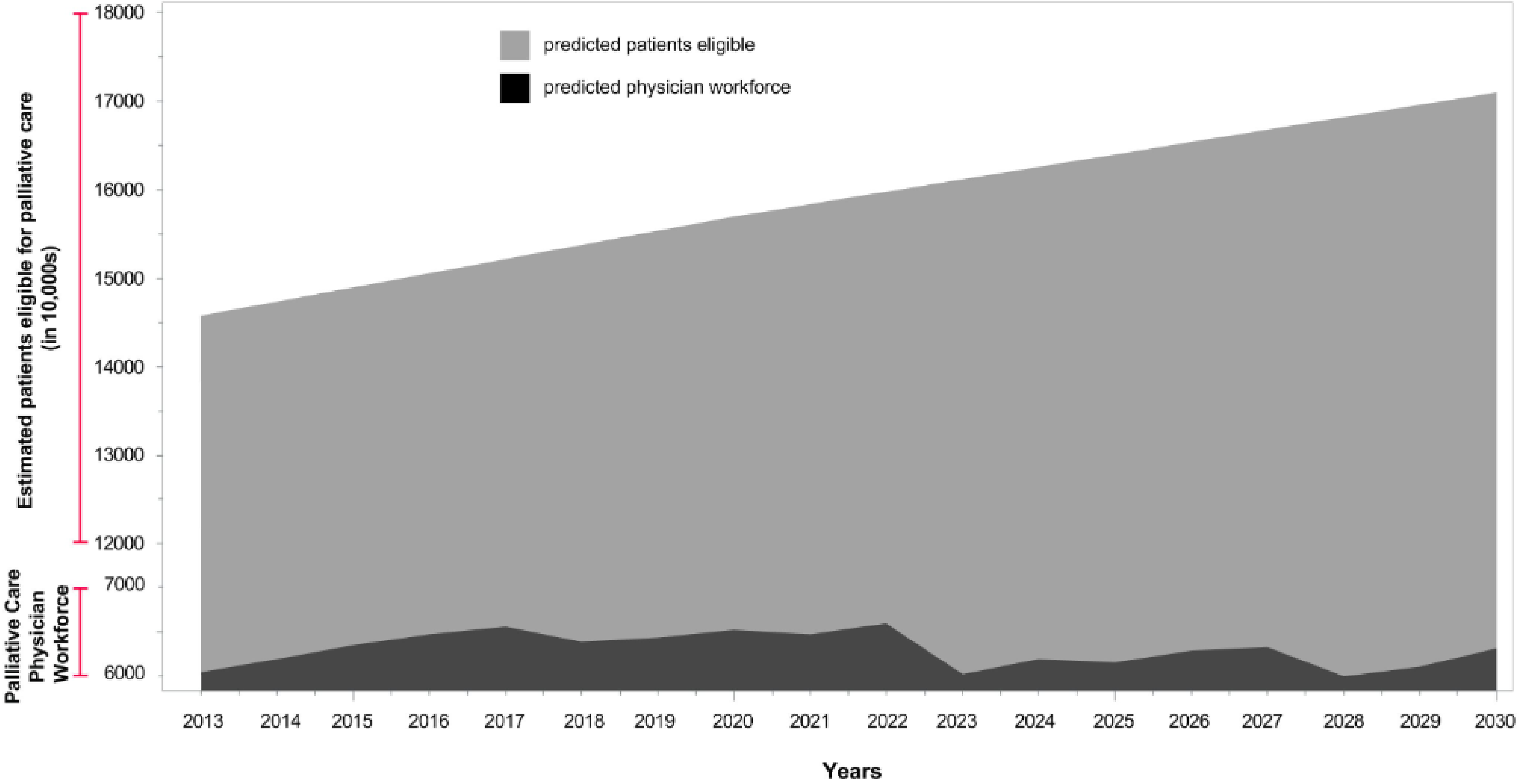
SUPPORT FOR EARLY PALLIATIVE INTERVENTION

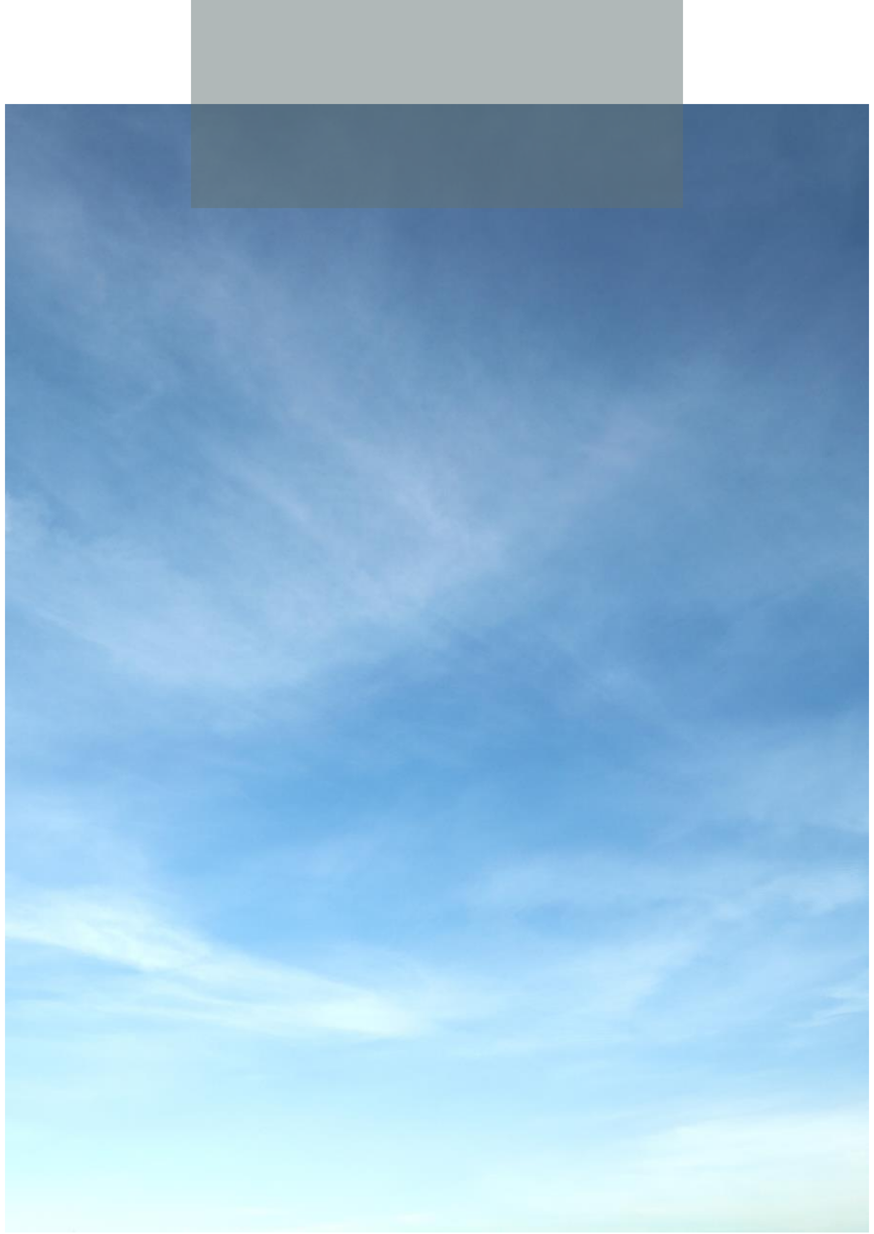
Early palliative care for patients with metastatic non-small-cell lung cancer

Jennifer S Temel[1], Joseph A Greer, Alona Muzikansky, Emily R Gallagher, Sonal Admane, Vicki A Jackson, Constance M Dahlin, Craig D Blinderman, Juliet Jacobsen, William F Pirl, J Andrew Billings, Thomas J Lynch

Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment

Alexi A Wright[1], Baohui Zhang, Alaka Ray, Jennifer W Mack, Elizabeth Trice, Tracy Balboni, Susan L Mitchell, Vicki A Jackson, Susan D Block, Paul K Maciejewski, Holly G Prigerson


predicted patients eligible
predicted physician workforce
Estimated patients eligible for palliative care (in 10,000s)
18000
17000
16000
15000
14000
13000
12000
Palliative Care Physician Workforce
7000
6000
2013
2014
2015
2016
2017
2018
2019
2020
2021
2022
2023
2024
2025
2026
2027
2028
2029
2030
Years



CASE - IDENTIFYING CHALLENGES

- time | follow-up = 20 min visit
- no-show, re-scheduling | unseen barriers to care
- "non-compliant"
- priorities can differ between patient & provider

PRIMARY PALLIATIVE CARE CHALLENGES

TIME

- Shortage of primary care physicians
- Most visit appointments are 20 minutes
- Can feel like an extra burden to try and accomplish

SUPPORT

- Working without support of interdisciplinary team model
- Often without support from social workers or case managers
- There are no clinical staff in roles to support palliative skills

CONTINUED EDUCATION

- Develop an understanding of palliative care
- Practice and comfort with palliative interventions and skills including counseling skills
- Overall, 97.5% of physician's expressed comfort in discussing ACP yet reported discussing advance directives with only 43% of appropriate patients

CASE: MRS. M

Transportation Barriers

- Office visits
- Lab appointments
- Screening mammogram

Family Structure

- Primary care-taker for her husband
- Rely on husband's adult children for transport
- Her family is in Puerto Rico

WHAT ARE SOCIAL DETERMINANTS OF HEALTH & WHY DO THEY MATTER?

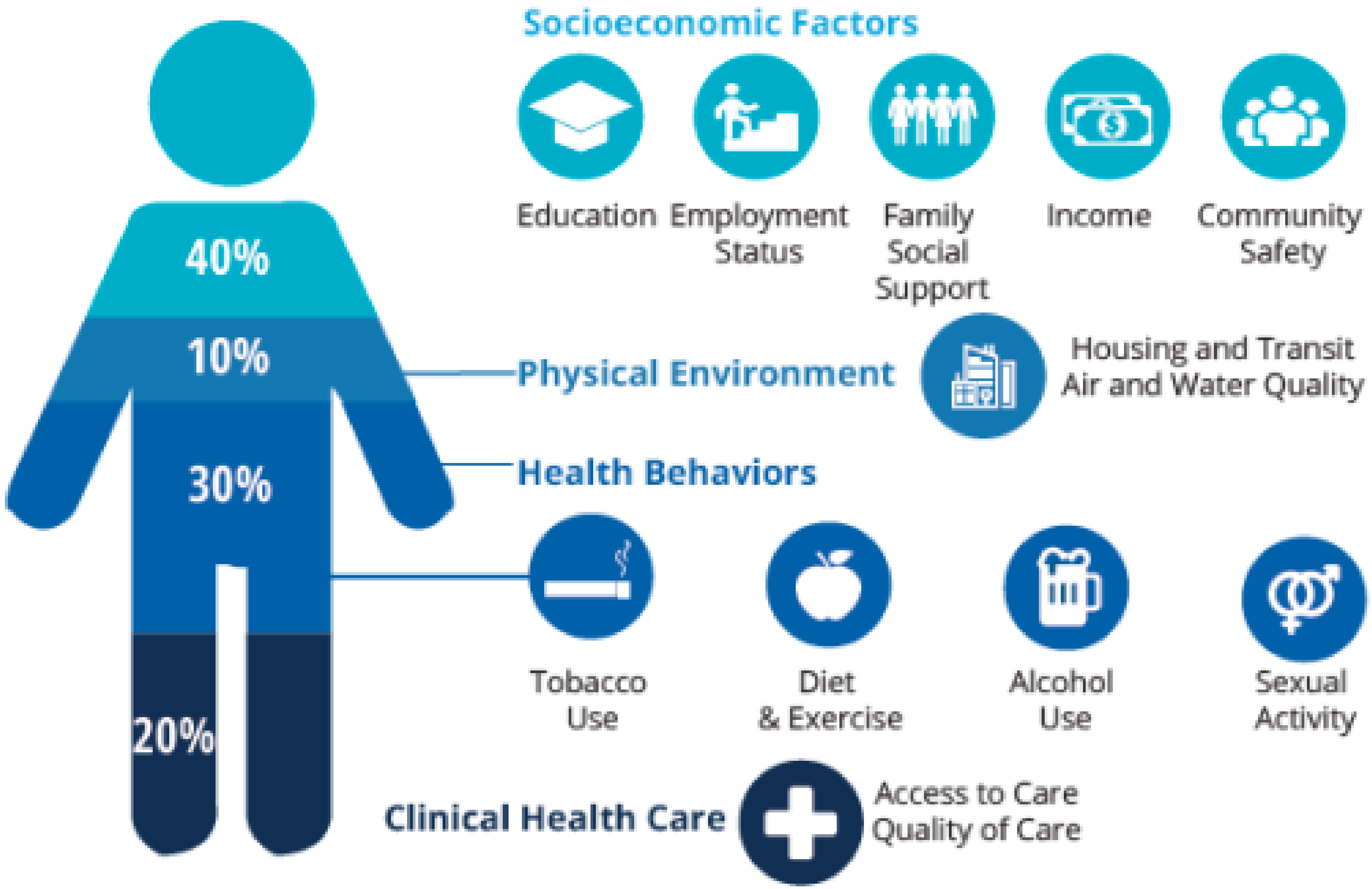
Neighborhood and Built Environment

Health Care and Quality

Social and Community Context

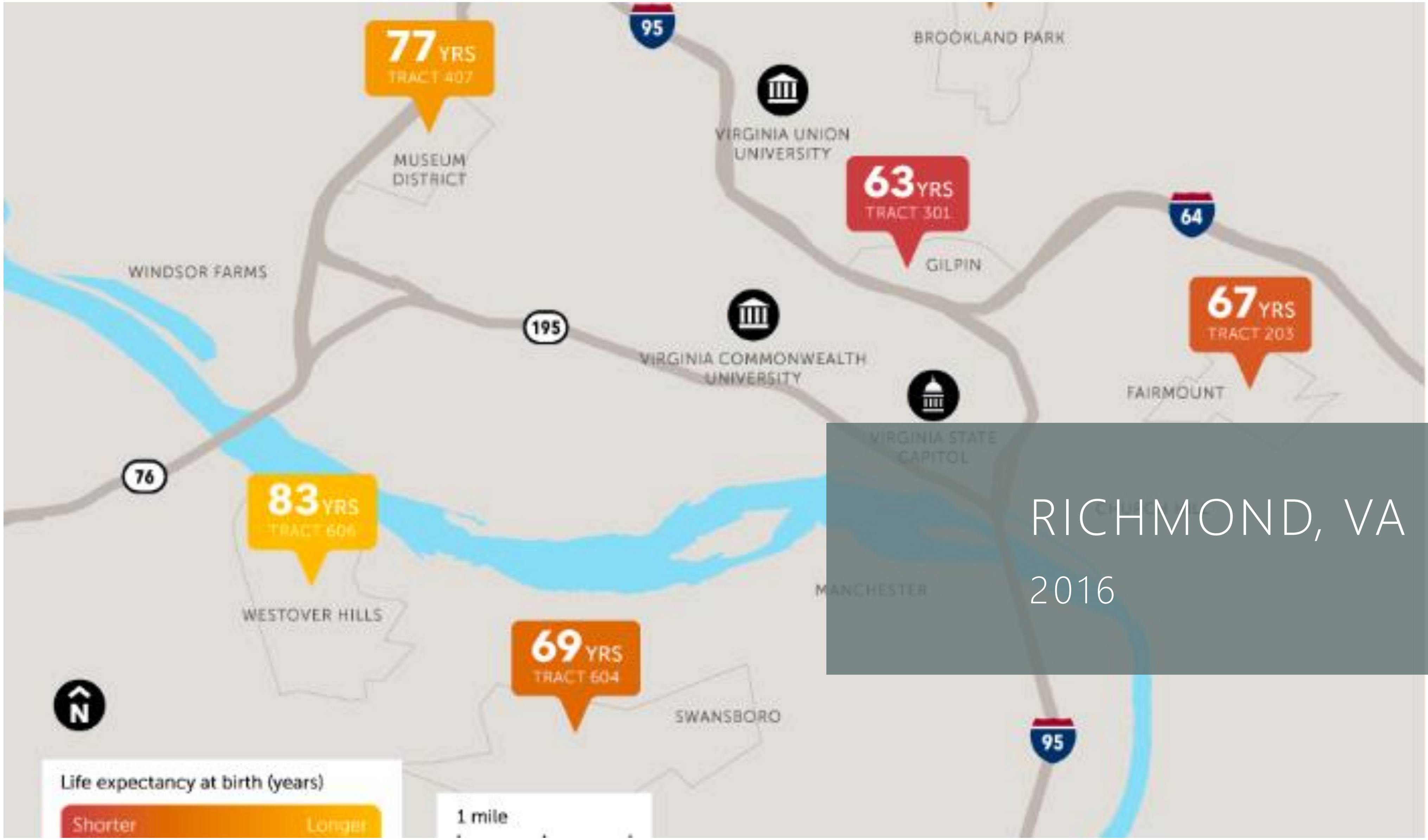
Education Access and Quality

Economic Stability



Hood, CM, Gennuso, KP, Swain, GR, & Catlin, BB. (2015). County health rankings: Relationships between determinant factors and health outcomes. *American Journal of Preventive Medicine.*

SDOH have been shown to have a greater influence on health than either genetic factors or access to healthcare services.

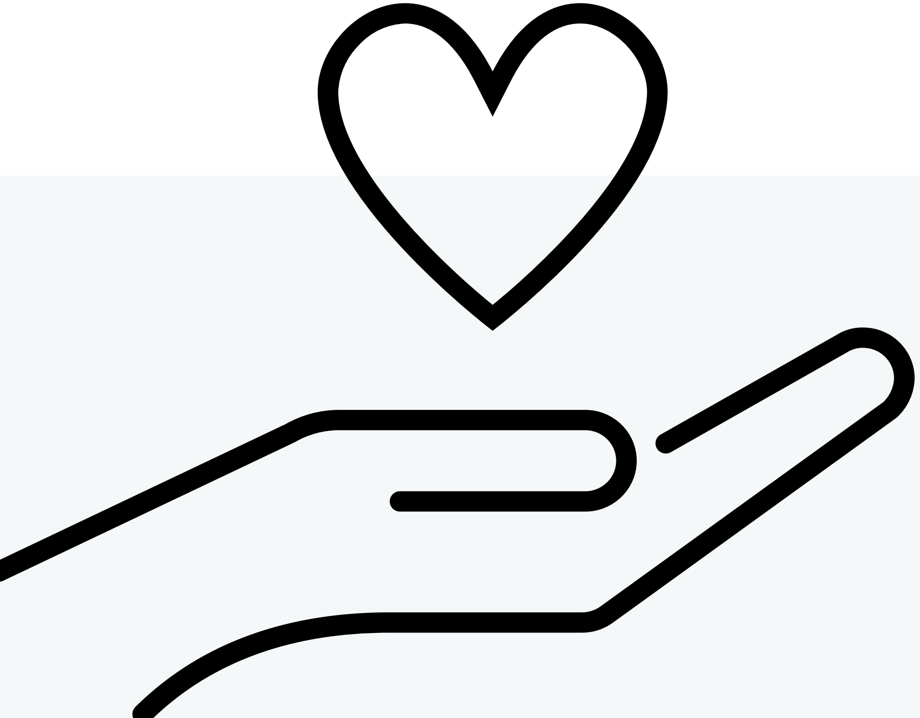


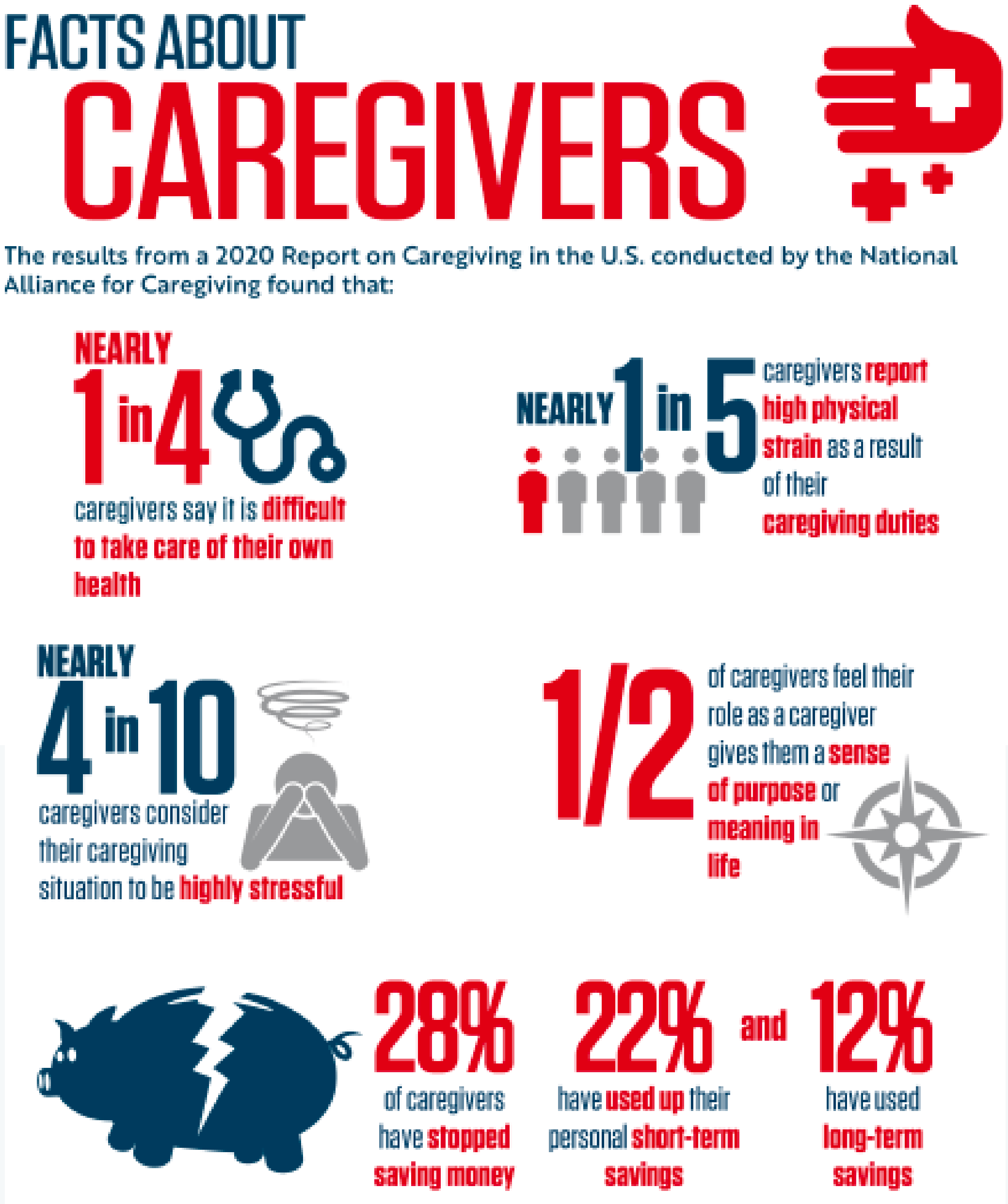
RICHMOND, VA

2016

Caregiving & Associated Burdens

- Unpaid
- Increased Stress
- Changes to their traditional family structure





FACTS ABOUT CAREGIVERS

The results from a 2020 Report on Caregiving in the U.S. conducted by the National Alliance for Caregiving found that:

NEARLY 1 in 4 caregivers say it is **difficult to take care of their own health**

NEARLY 1 in 5 caregivers report **high physical strain** as a result of their **caregiving duties**

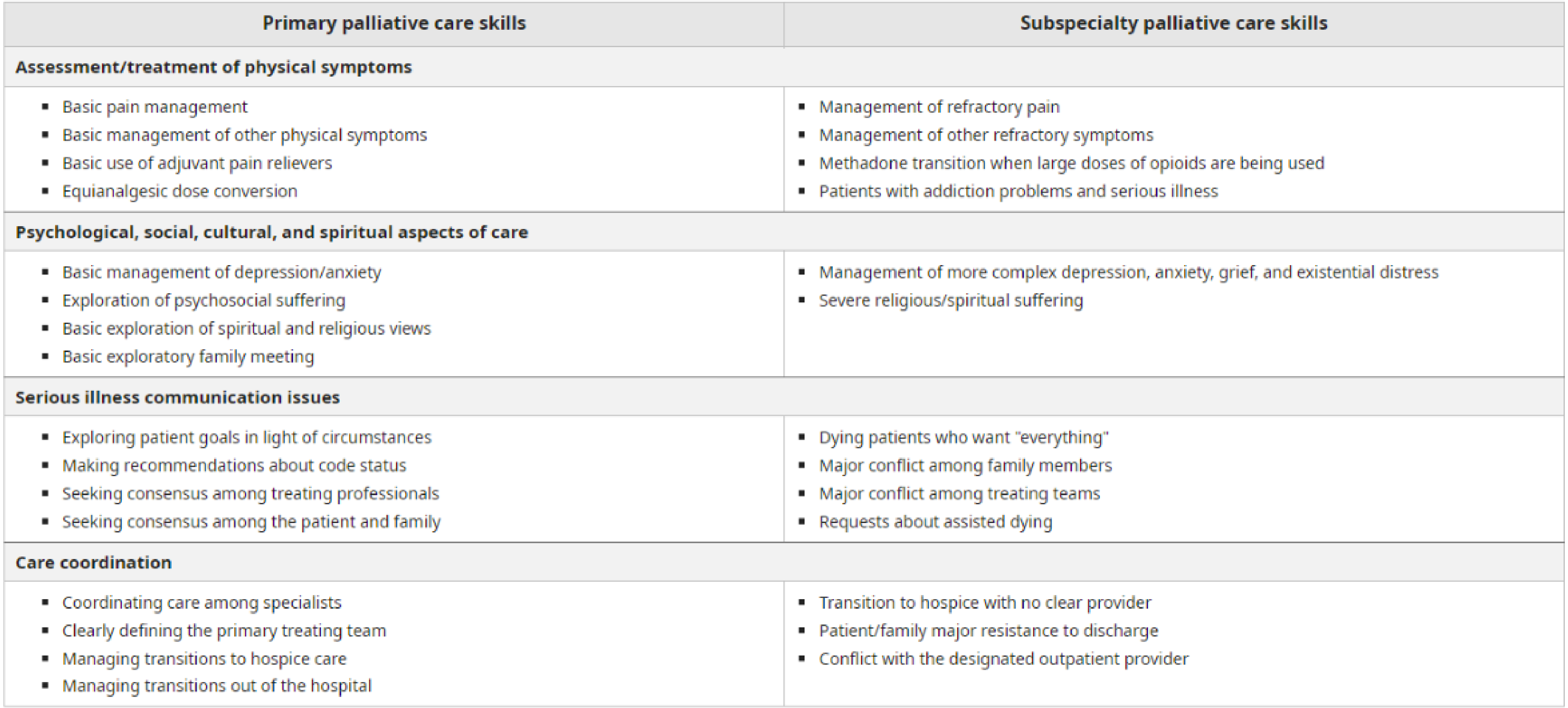
NEARLY 4 in 10 caregivers consider their caregiving situation to be **highly stressful**

1/2 of caregivers feel their role as a caregiver gives them a **sense of purpose** or **meaning in life**

28% of caregivers have **stopped saving money**

22% have **used up** their personal **short-term savings**

and **12%** have used **long-term savings**



Primary palliative care skills	Subspecialty palliative care skills
Assessment/treatment of physical symptoms	
- Basic pain management - Basic management of other physical symptoms - Basic use of adjuvant pain relievers - Equianalgesic dose conversion	- Management of refractory pain - Management of other refractory symptoms - Methadone transition when large doses of opioids are being used - Patients with addiction problems and serious illness
Psychological, social, cultural, and spiritual aspects of care	
- Basic management of depression/anxiety - Exploration of psychosocial suffering - Basic exploration of spiritual and religious views - Basic exploratory family meeting	- Management of more complex depression, anxiety, grief, and existential distress - Severe religious/spiritual suffering
Serious illness communication issues	
- Exploring patient goals in light of circumstances - Making recommendations about code status - Seeking consensus among treating professionals - Seeking consensus among the patient and family	- Dying patients who want "everything" - Major conflict among family members - Major conflict among treating teams - Requests about assisted dying
Care coordination	
- Coordinating care among specialists - Clearly defining the primary treating team - Managing transitions to hospice care - Managing transitions out of the hospital	- Transition to hospice with no clear provider - Patient/family major resistance to discharge - Conflict with the designated outpatient provider

How can the palliative team help to support?

Visibility

- Referral criteria
- Community involvement

Education

- Learning at every level

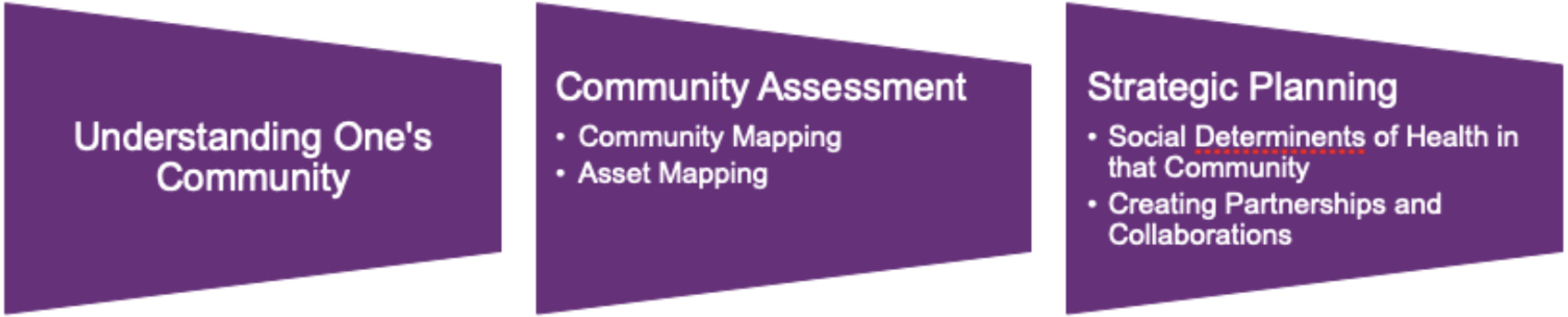
Interprofessional Support

- QI projects
- Utilize technology
- Add value

Community Involvement

- Many primary care practices do not operate with interdisciplinary team member support
- Important to create visibility of palliative care as a resource for specialty referral, especially in instances of high-risk patients
- responsibility to have a good understanding of where to find community resources and to be involved in advocacy, quality improvement projects, and understand who the stakeholders are so palliative care can be prioritized in many different avenues

Community Assessment as the First Step:



Understanding One's Community

Community Assessment
- Community Mapping
- Asset Mapping

Strategic Planning
- Social Determinents of Health in that Community
- Creating Partnerships and Collaborations

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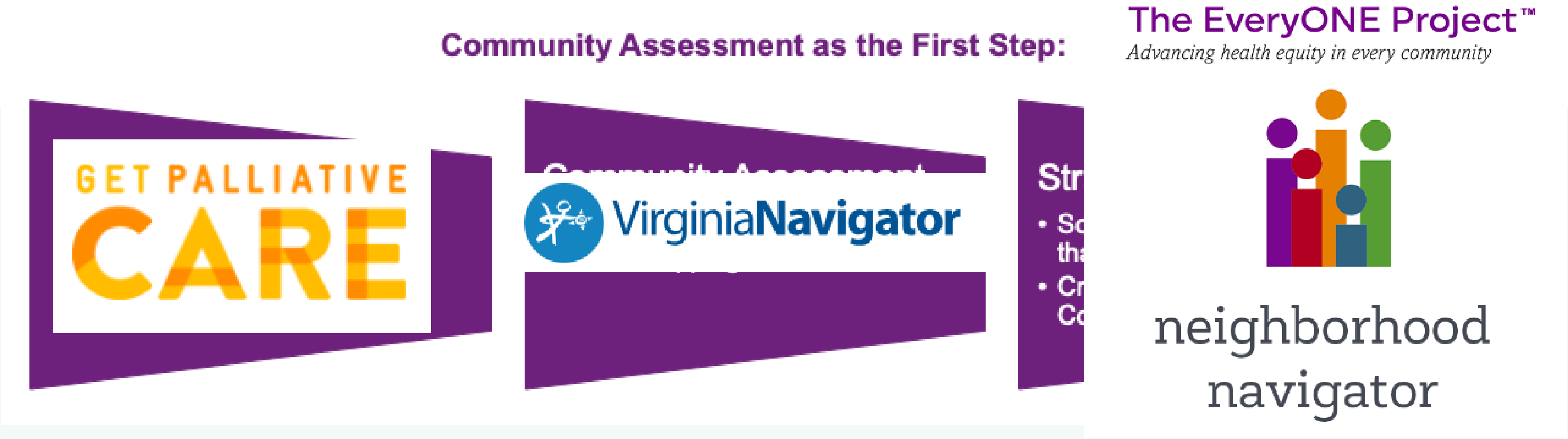


Community Assessment as the First Step:

Optimize Workflow and Efficiency

Key Visits
- Transition of Care
- Medicare Wellness Visits

Modify Templates
- Rapid palliative assessment
- Reminders

Maximize EMR
- Dot Phrases
- Quick Tools
- Triggers for consult consideration

Power to the people

Similar to increased compliance with colon cancer screenings after mailing iFOBT testing kits, there has been evidence that mailing out advanced care planning materials with education also increased rates of completion.

"After 28 weeks, 1.5% (5/332) of patients in the physician reminder group, 14% (38/277) in the physician reminder plus patient mailing group, and 1.8% (5/286) in the control group had completed advance directives. In multivariate analyses, patients in the physician reminder plus patient mailing group were much more likely than controls to have completed advance directives"

Clinical Trial > Am J Med. 2004 Sep 1;117(5):318-24. doi: 10.1016/j.amjmed.2004.03.027.

Improving completion of advance directives in the primary care setting: a randomized controlled trial

Heather Heiman [1], David W Bates, David Fairchild, Shimon Shaykevich, Lisa Soleymani Lehmann

Power to the people

PREPARE™ for your care

- Prepare for your care can be a tool used for follow-up instead of classic mail follow-up
- Involved in Research/QI
- Electronic FU and resource; even in the waiting room?

Education at every level

Includes: medical students, residents, fellows and as a part of continuing medical education initiative for all providers and members of IDT team.

Palliative Education Curriculum:

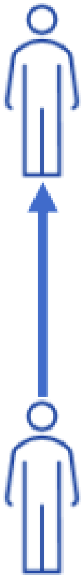
- Addressing Physical Needs
  - Pain & Other Physical Symptoms
  - Functional Status
- Addressing Psychological/Psychiatric Needs
  - Depression and Anxiety
  - Grief/Bereavement
- Addressing Social and Spiritual Needs
- Communicating w Patients and Families

Include acknowledgement and training regarding SDoH and health equity:

- Case Studies & Simulations
- Cultural Competency Training
- Community Engagement
- Guest Speakers
- Interprofessional Education

Primary palliative education should include SDOH

Patient 1



- Cancer related pain secondary to spine mets
- Has insurance
- Flexible job
- Good family support
- Safe housing
- Reliable transportation

Pain assessment and management for Person 1 is

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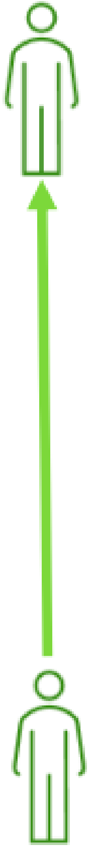
to Patient 2

Patient 2

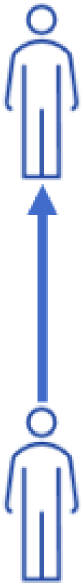


- Cancer pain related pain secondary to spine mets
- Does not have insurance
- No family or friends to help support
- No transportation
- May get fired from job
- Unstable housing

Considerations: How is the social component of "total pain" affecting their overall pain control? How much of pain reporting is related to social pain? What are ways these social barriers can be addressed to improve suffering?

Primary palliative education should include SDOH

Patient 1



- Incurable cancer, limited prognosis
- Has insurance
- Flexible job
- Good family support
- Safe housing
- Reliable transportation

Likewise, goals of care discussion for Person 1 is

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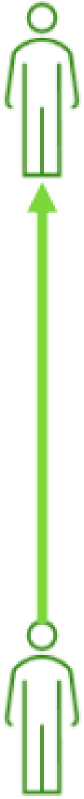
to Patient 2

Patient 2



- Incurable cancer, limited prognosis
- Does not have insurance
- No family or friends to help support
- No transportation
- May get fired from job
- Unstable housing

Considerations: How is the lack of social support affecting the patient's perception of their medical decision making? Do they have enough support for the care plan they want? How can we arrange the services they need for their desired care plan? Is low trust/lack of trust an issue?

Back to Mrs. M

Figure 1. Primary Palliative Care Need and Possible Interventions

High-Risk Patients (at risk for dying in next 1 to 2 years)

In addition to all interventions for At-Risk Patients:

- Formalize assessment of functional status, needs for caregivers, and medical equipment
- Formalize screening for caregiver burnout/distress
- Refer to specialty palliative care for additional support, if available

At-Risk Patients (with serious illness or illnesses)

In addition to all interventions for All Patients:

- Formalize routine symptom assessment (pain, non-pain physical symptoms, depression, anxiety)
- Develop pathways for managing identified symptoms and referring to appropriate specialists when needed
- Develop routine visits to clarify state of medical conditions, provide information on prognosis (if desired), and anticipate future decisions
- Develop routine visits to clarify patient/family concerns, goals of care
- Develop routine visits to discuss end-of-life concerns and wishes

All Patients in the Practice

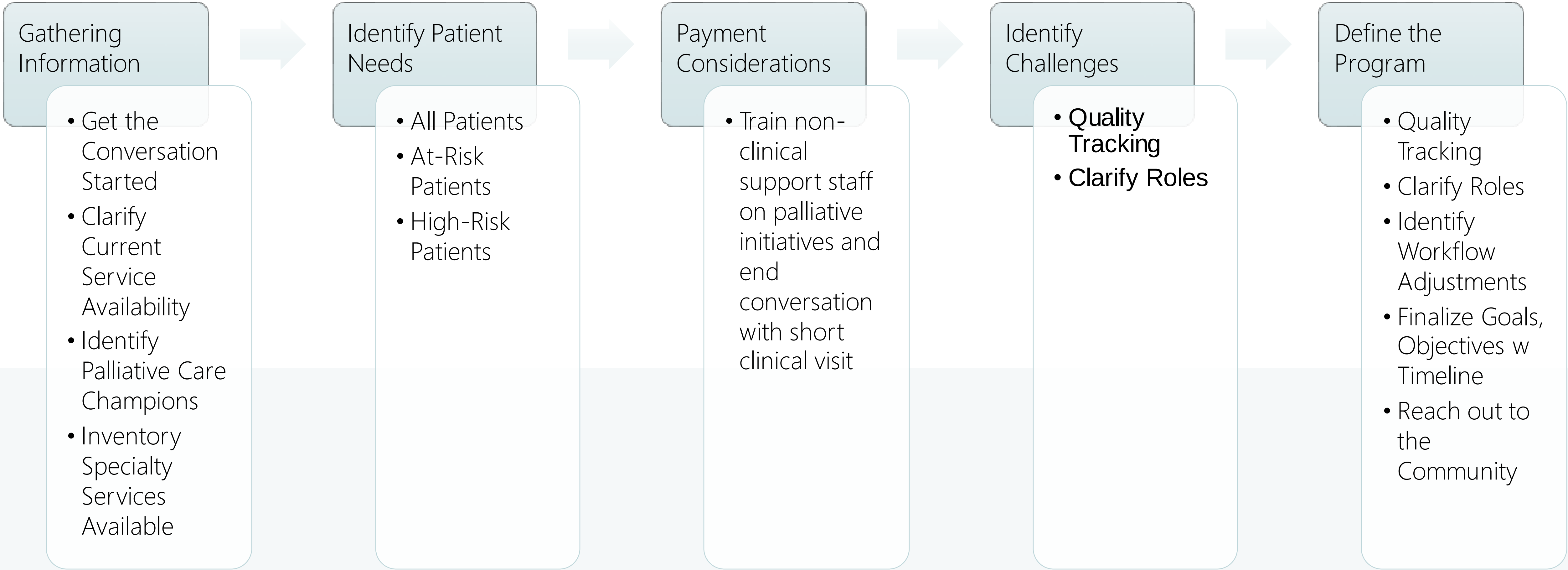
- Screen for prior advance directive completion for all adults (or adults over age 50) and provide support and information to encourage completion
- Identify and document surrogate decisionmaker(s)
- Conduct discussion of preferences for medical information sharing
- Ensure electronic health record has the ability to document all of the above

develop triggers for involving specialty palliative

develop plan for routine visits

begin advanced care planning discussions

Integrating Primary Palliative Care as outlined by the California Healthcare Foundation



Gathering Information

- Get the Conversation Started
- Clarify Current Service Availability
- Identify Palliative Care Champions
- Inventory Specialty Services Available

Identify Patient Needs

- All Patients
- At-Risk Patients
- High-Risk Patients

Payment Considerations

- Train non-clinical support staff on palliative initiatives and end conversation with short clinical visit

Identify Challenges

- Quality Tracking
- Clarify Roles

Define the Program

- Quality Tracking
- Clarify Roles
- Identify Workflow Adjustments
- Finalize Goals, Objectives w Timeline
- Reach out to the Community

IN SUMMARY

- Integrating primary palliative skills in the primary care setting can be challenging
- Identifying key barriers and addressing them together with continued education, quality improvement and community support is essential
- Recognizing that part of palliative care is addressing social determinants of health and by doing so can help improve patient's quality of life

What are strategies or initiatives that you have seen in your own community and health systems that have improved practice of primary palliative skills?

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