7ᵗʰ Symposium on Primary Breast Cancer in Older Women

Involving Patients and Caregivers

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National Institute of Aging

Overview

The critical role of caregivers

Geriatric assessment as a tool to involve patients and caregivers in treatment decisions

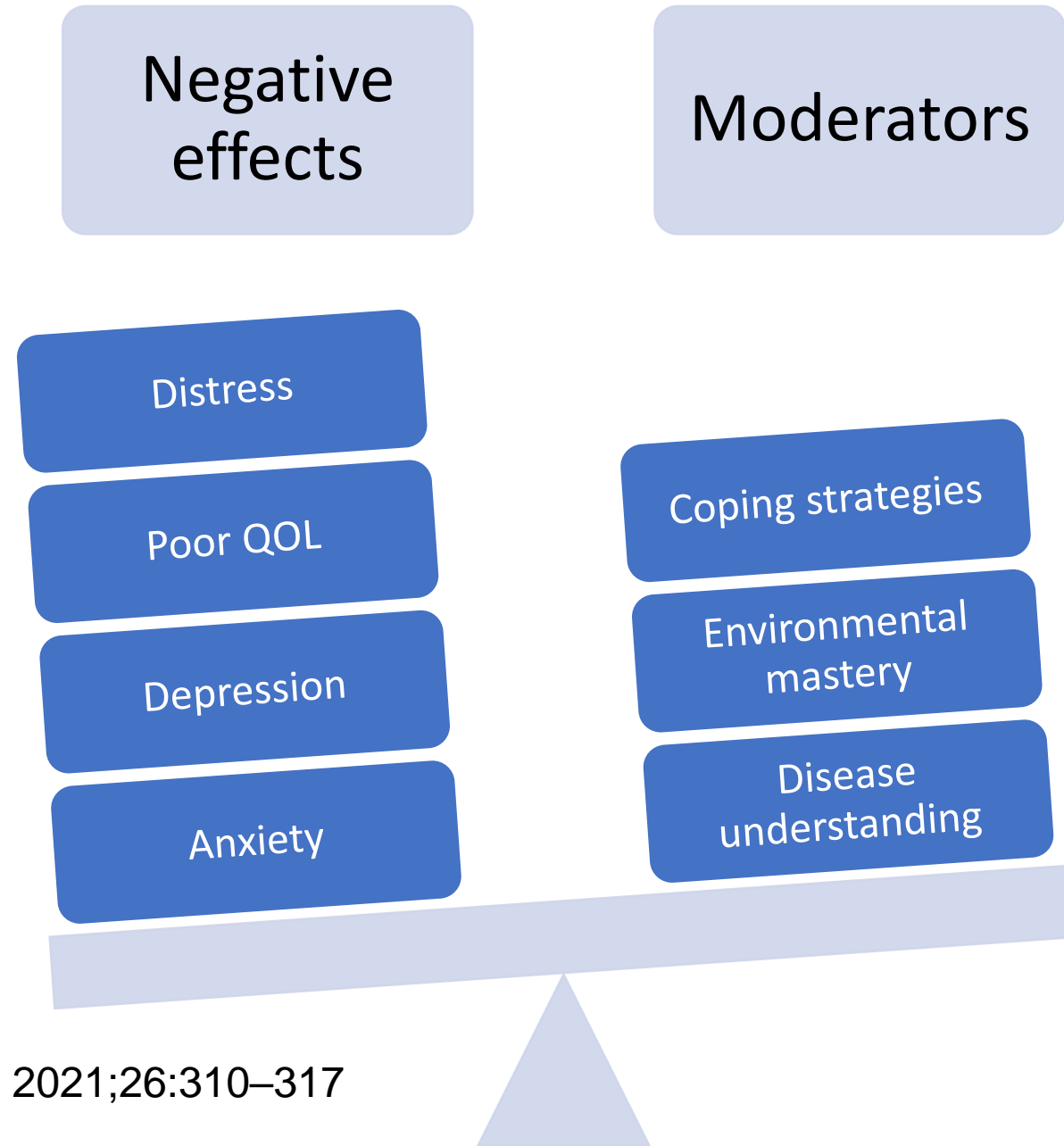The importance of involving patients and caregivers in research

Our approach: 4Ms and Patient Priorities Care

The crucial role of caregivers

Set schedules → Manage symptoms → Assist with daily activities → Navigate healthcare → Advocate → Assist with decisions

- Caregivers perform a wide array of critical functions across a broad spectrum of skills
- A focus on the clinician-patient relationship forgets the important role that caregivers play in the physical and mental health of a patient with cancer

The balancing act of being a caregiver

Negative effects

Moderators

Distress

Poor QOL

Depression

Anxiety

Coping strategies

Environmental mastery

Disease understanding

Loh KP et al. The Oncologist 2021;26:310–317

Breast cancer caregiving

Caregivers

- Most likely male partners
- Have severe burden
- Unmet needs
- Need multiple types of support

Dyad
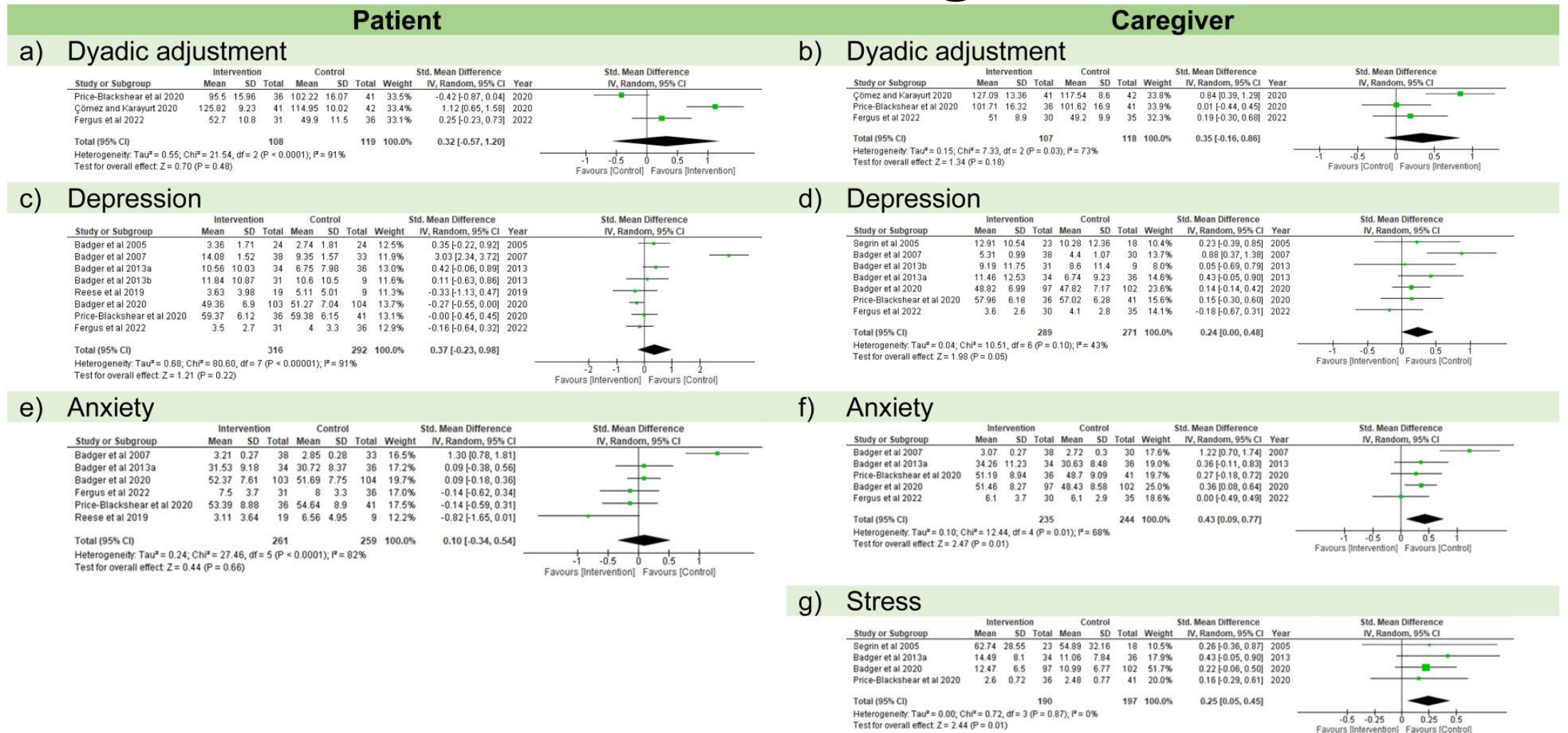
- Communication avoidance
- Patient outcome and prognosis affects caregiver depression, anxiety, QOL

Patients

- Body changes
- High levels of comorbidity if older
- Functional impairments
- ***Competing risks for death***

Tao L et al. Supportive Care in Cancer; 2022:7789-7799.

Tan JYA et al. J Telemedicine and Telecare, 2023:1-14.

Mental health interventions for patients with breast cancer and their caregivers

Tan JYA et al. J Telemedicine and Telecare, 2023.1-14.

What do patients want?
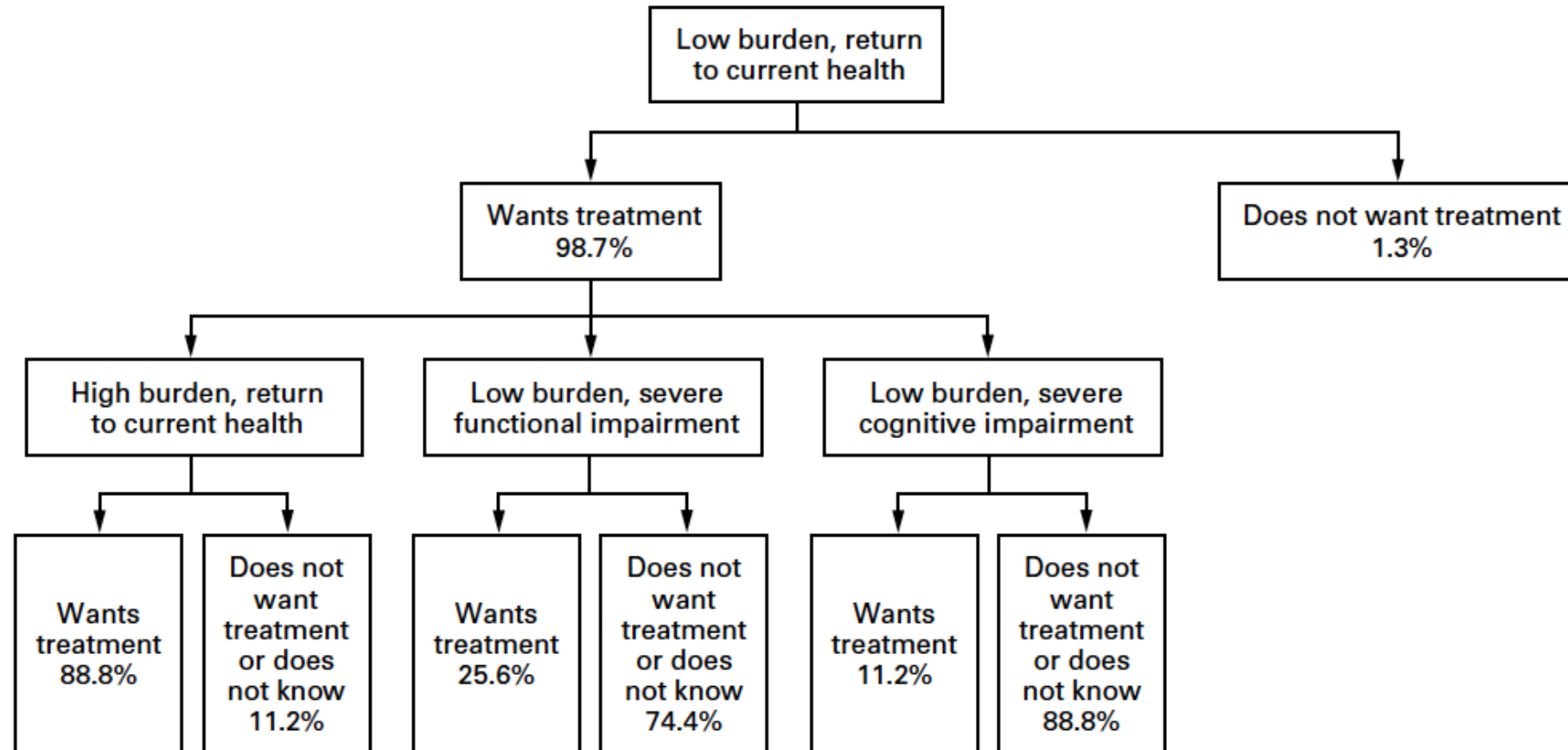
Figure 2. Treatment Preferences According to the Burden and Outcome of Treatment.

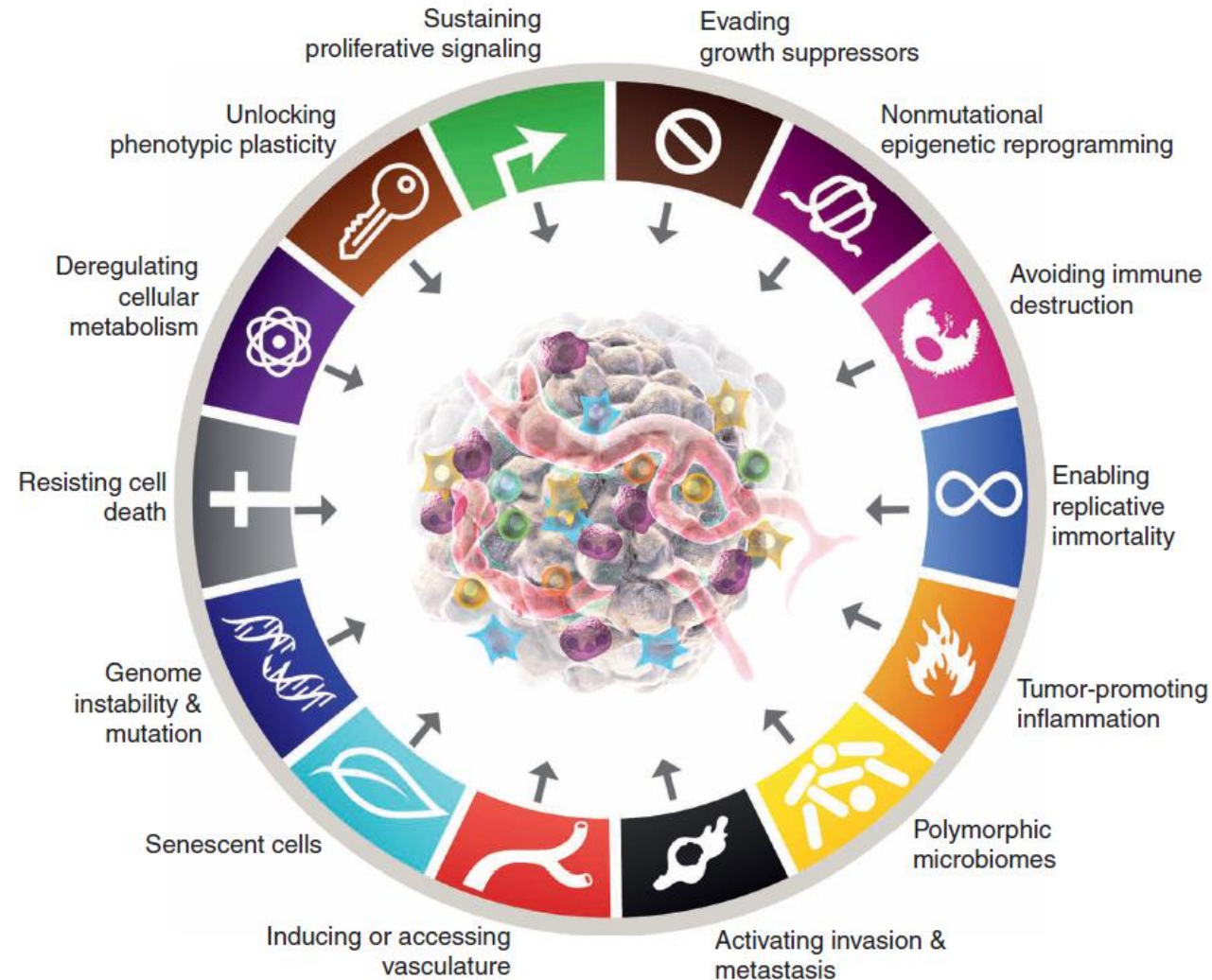Fried T. N Engl J Med. 2002;346:1061-6.

Patient preferences

- ## Quality of life trade-offs
  - Terri Fried's classic study: 74% would forego low burden treatment that caused functional impairment, 89% if cognitive impairment
  - In a survey of Medicare beneficiaries, 83.9% would not want potentially life-prolonging drugs that made them feel worse all the time

- ## Having the conversation
  - In a cross-sectional survey of older adults, 70% believed their healthcare providers knew their priorities, but only 36% had actually had a conversation
  - Concordance between physician perception and patient preferences only about 50%

Fried *NEJM* 2002
Barnato *Med Care* 2007

Case *JAGS* 2015
Caocci *Leuk Res* 2015
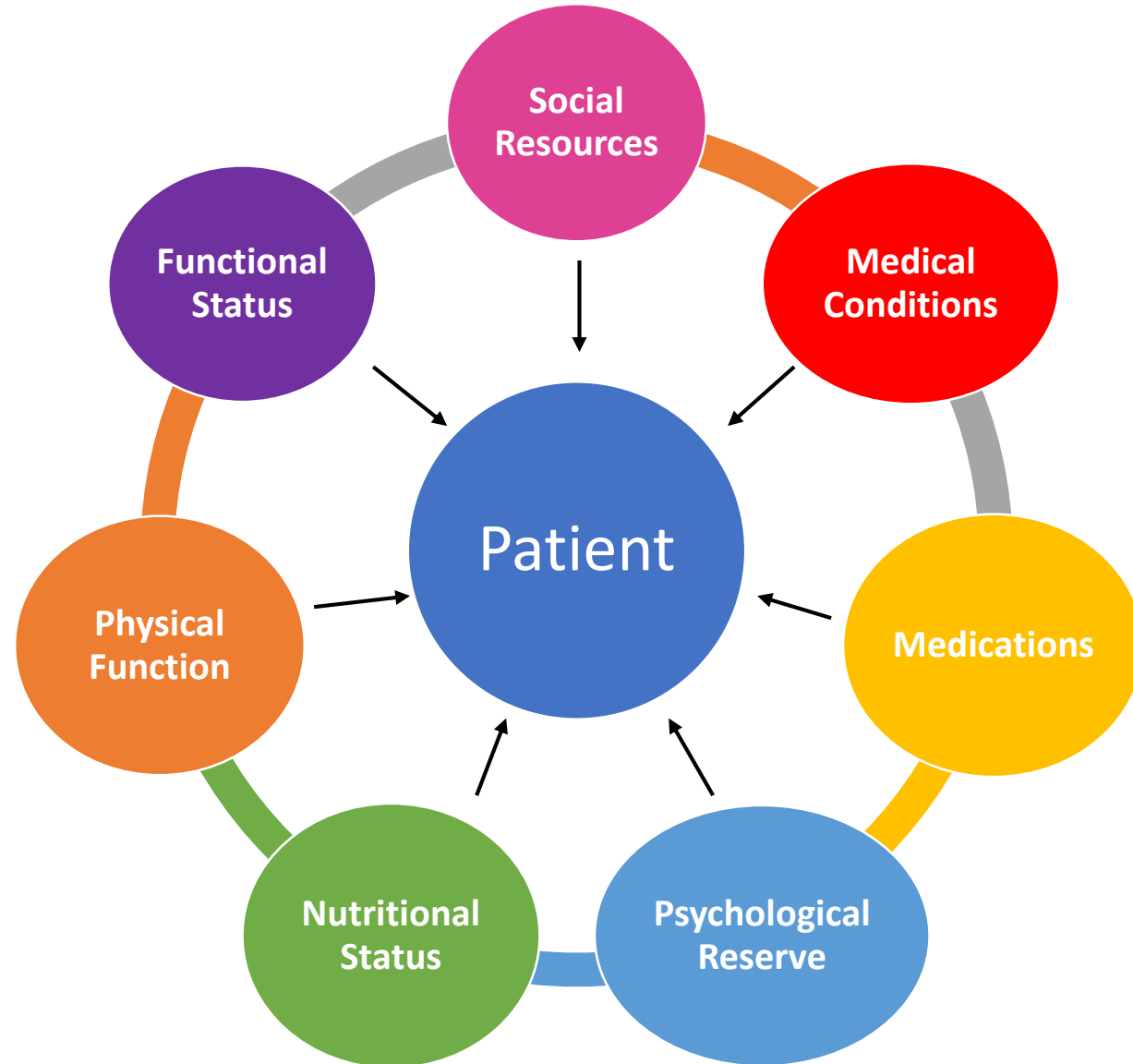
How patients want to make decisions
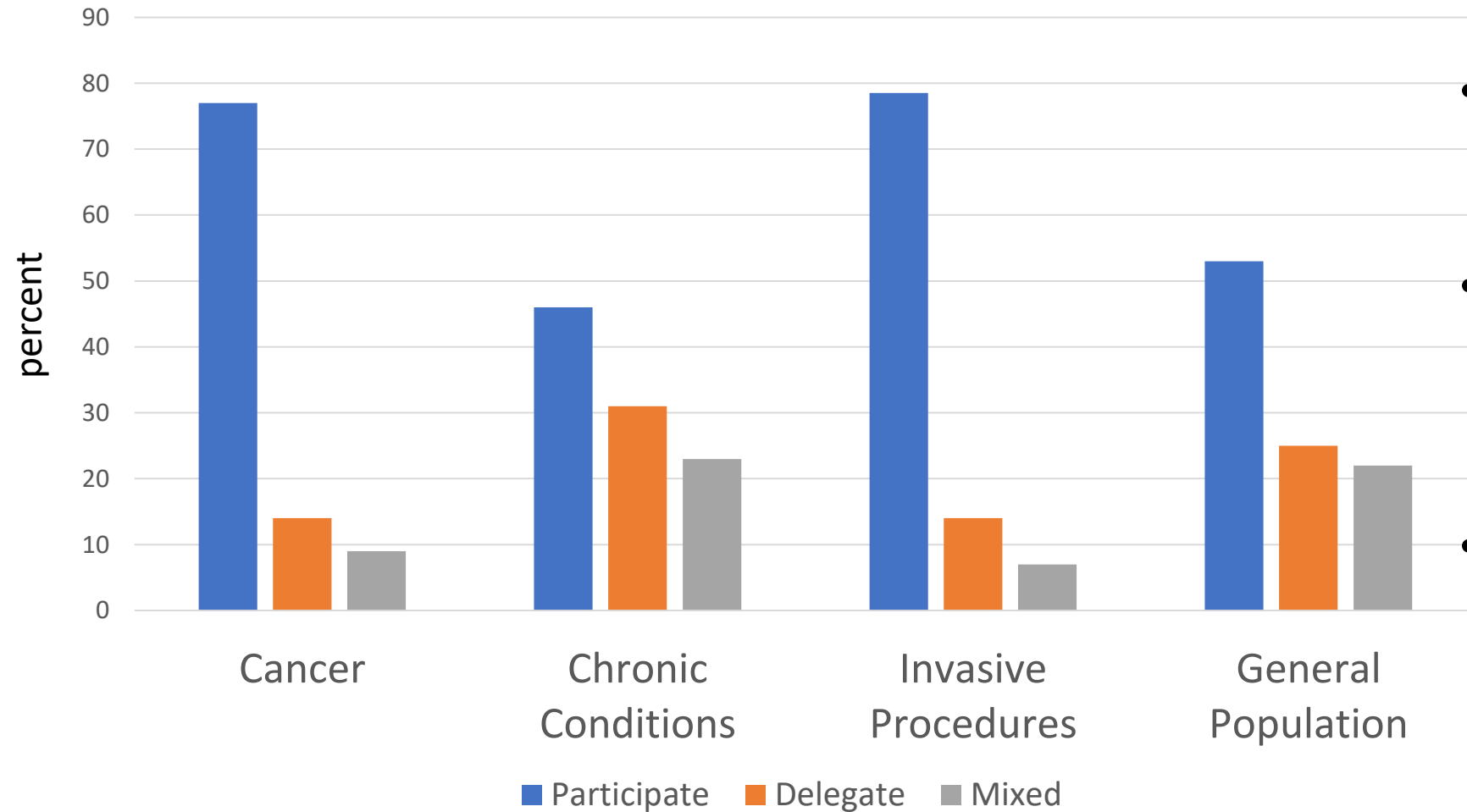
- Recognize when older adult faces a "preference sensitive" decision
- Ensure that older adults are adequately informed about benefits and harms
- Elicit patient/caregiver preferences after they are sufficiently informed

Chewning. *Patient Educ Couns*. 2012 January ; 86(1): 9–18.   AGS Task Force on Multimorbidity, J Amer Geriatr Soc 2012

The Oncologist's Focus

Hanahan D. Cancer Biology, 2022.
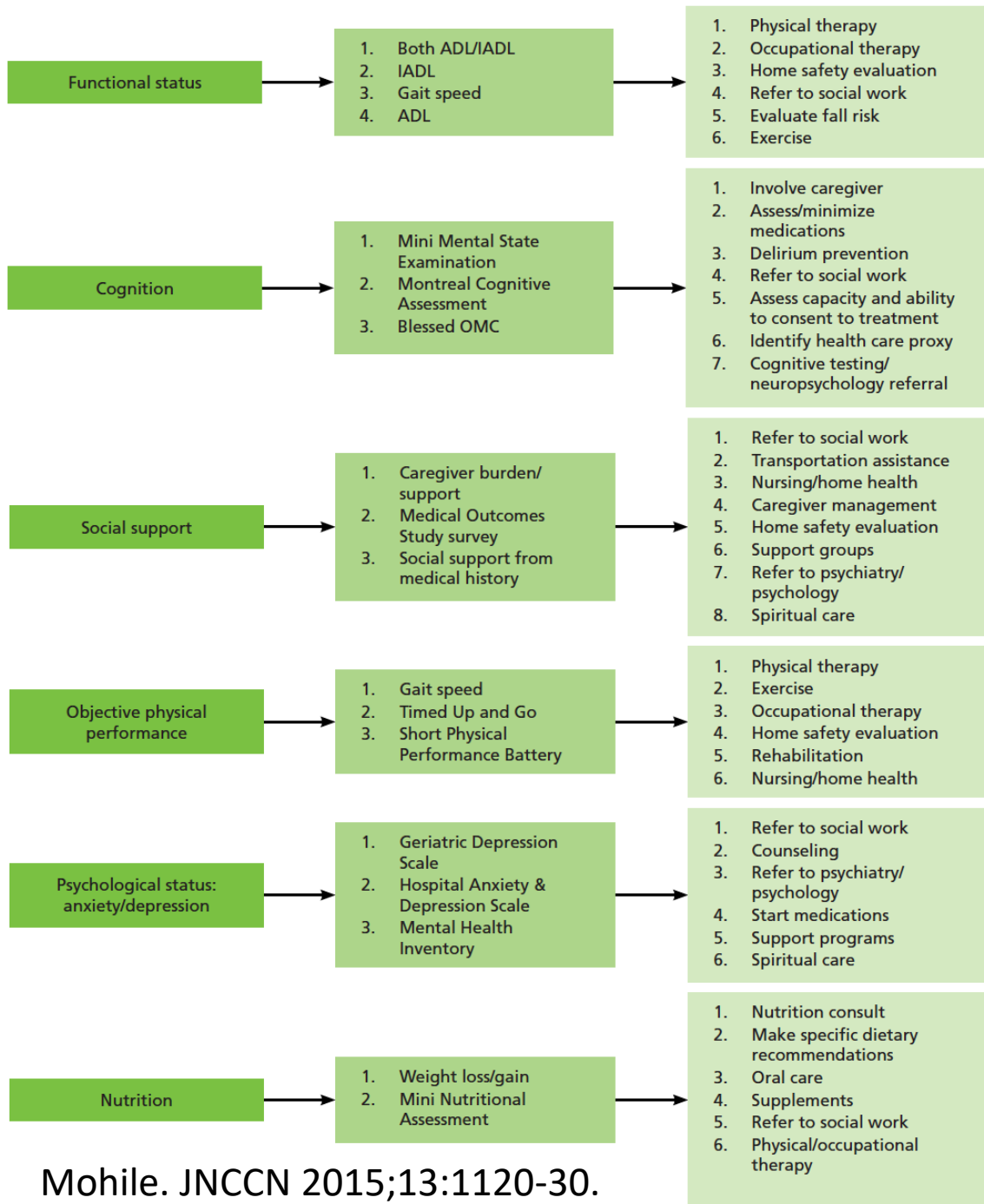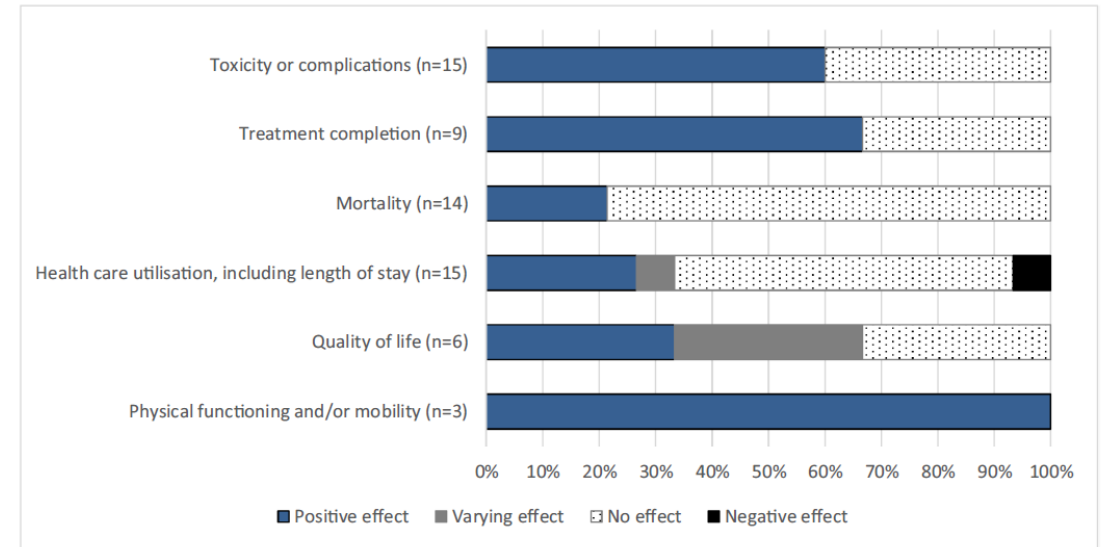
The Geriatrician's Focus

GA components

- Functional status
- Physical performance
- Comorbidity
- Medication use
- Psychological assessment
- Cognition
- Nutrition
- Social support

GA-driven interventions

Functional status	1. Both ADL/IADL 2. IADL 3. Gait speed 4. ADL	1. Physical therapy 2. Occupational therapy 3. Home safety evaluation 4. Refer to social work 5. Evaluate fall risk 6. Exercise
Cognition	1. Mini Mental State Examination 2. Montreal Cognitive Assessment 3. Blessed OMC	1. Involve caregiver 2. Assess/minimize medications 3. Delirium prevention 4. Refer to social work 5. Assess capacity and ability to consent to treatment 6. Identify health care proxy 7. Cognitive testing/ neuropsychology referral
Social support	1. Caregiver burden/ support 2. Medical Outcomes Study survey 3. Social support from medical history	1. Refer to social work 2. Transportation assistance 3. Nursing/home health 4. Caregiver management 5. Home safety evaluation 6. Support groups 7. Refer to psychiatry/ psychology 8. Spiritual care
Objective physical performance	1. Gait speed 2. Timed Up and Go 3. Short Physical Performance Battery	1. Physical therapy 2. Exercise 3. Occupational therapy 4. Home safety evaluation 5. Rehabilitation 6. Nursing/home health
Psychological status: anxiety/depression	1. Geriatric Depression Scale 2. Hospital Anxiety & Depression Scale 3. Mental Health Inventory	1. Refer to social work 2. Counseling 3. Refer to psychiatry/ psychology 4. Start medications 5. Support programs 6. Spiritual care
Nutrition	1. Weight loss/gain 2. Mini Nutritional Assessment	1. Nutrition consult 2. Make specific dietary recommendations 3. Oral care 4. Supplements 5. Refer to social work 6. Physical/occupational therapy

Mohile. JNCCN 2015;13:1120-30.

- GA leads to:
- More goals of care discussions and improved communication
- Improved likelihood of treatment completion
- Lower toxicity/complication rates

Hamaker M, Lund C, et al. J Geriatr Oncol. 2022; 13(6):761-777.

The Value of GA

- Prognostic value
- Focus on unmet needs, quality of life
- Priorities aligned care
- Early referral to palliative care

Toxic Effects	GAIN (n=402)	Standard of Care (n=203)	P value
Grade 3+ toxicity	50.5%	60.6%	0.02
Change in advance directives	28.4%	13.3%	<0.001

Li D, et al. JAMA Oncol. 2021;7: e214158.

The Value of GA

Figure 2. Patient and Caregiver Satisfaction
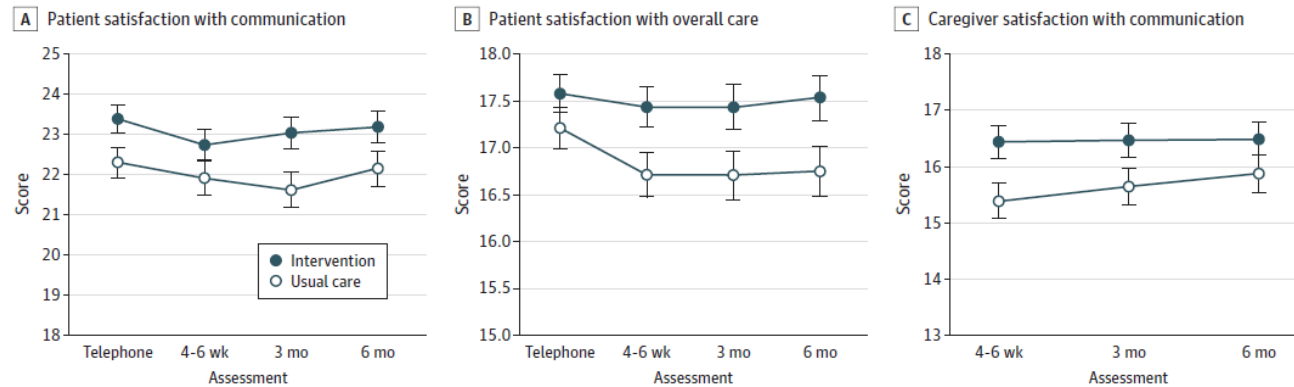
A, Patient satisfaction with communication about aging-related concerns. B, Patient satisfaction with overall care. C, Caregiver satisfaction with communication about the patient's age-related conditions. Scores were derived using modified versions of the Health Care Climate Questionnaire. The telephone assessment was 7 to 14 days after the audio-recorded clinic visit.

Improving patient and caregiver satisfaction

and communication.

Figure 3. Conversations About Aging-Related Conditions

Mohile SG, et al. JAMA Oncol. 2020;6:196-204.
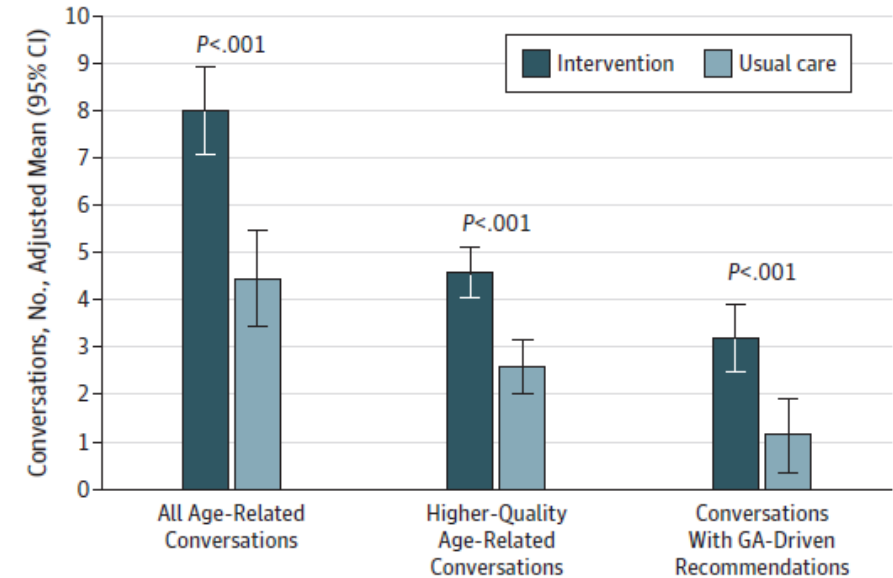
The success of COACH engaging patients and caregivers

- Active stakeholder group (Stakeholders for Care in Oncology and Research for our Elders board, "SCOREboard")
- Engaged PI
- Empowered co-chair
- Staff dedicated to partner engagement
- Funding for in-person meetings and compensatio
- Clear roles
- Additional engagement opportunities

Research Team Introduces Material to SCOREboard for review

SCOREboard Review and Provide Input

Together SCOREboard & Research Team Decide How to Implement Input

SCOREboard Review & Approve Final Product with Input Implemented
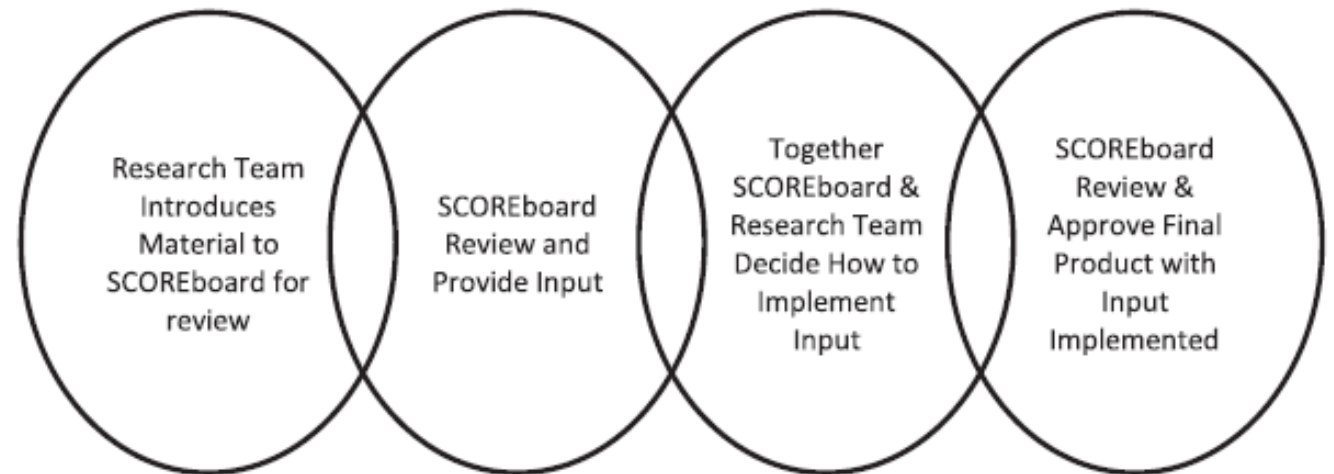
Gilmore NJ, et al. Cancer; 2019: 4124-33

Making cancer care "age-friendly"
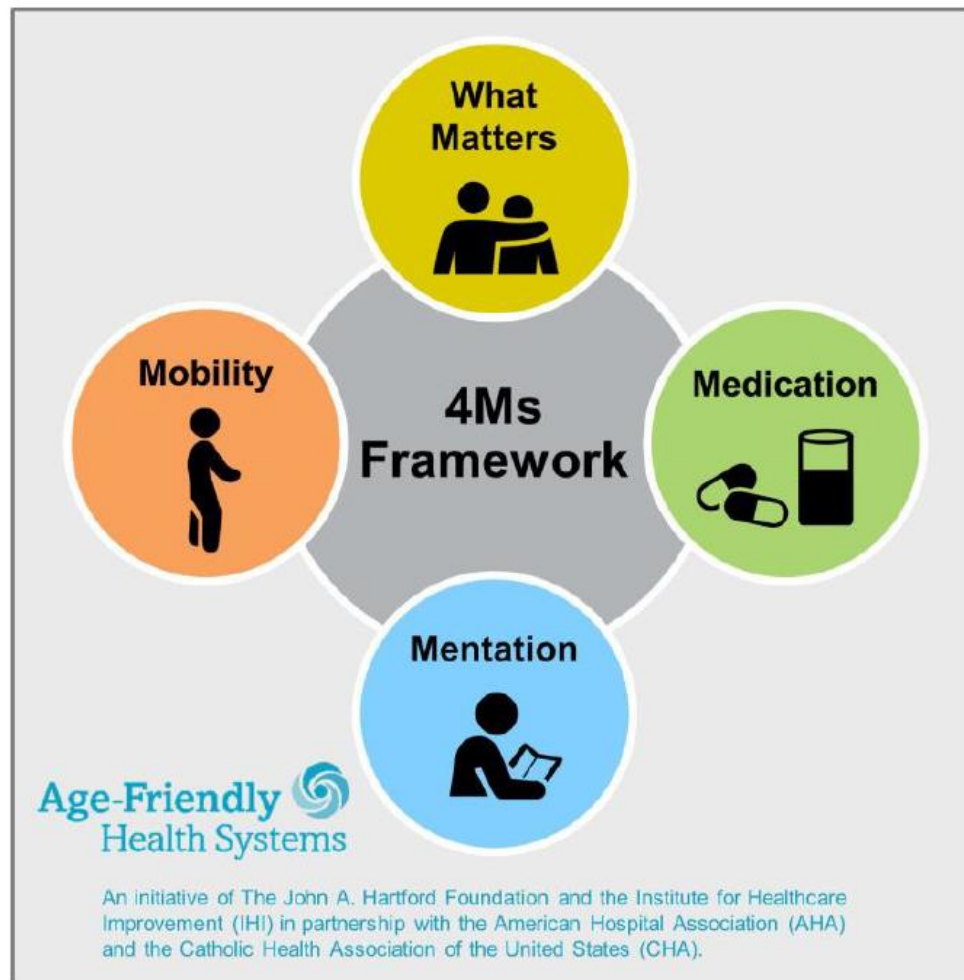
What Matters
Know and align care with each older adult's specific health outcome goals and care preferences including, but not limited to, end-of-life care, and across settings of care.

Medication
If medication is necessary, use Age-Friendly medication that does not interfere with What Matters to the older adult, Mobility, or Mentation across settings of care.

Mentation
Prevent, identify, treat, and manage dementia, depression, and delirium across settings of care.

Mobility
Ensure that older adults move safely every day in order to maintain function and do What Matters.

Institute for Healthcare Improvement. Age-Friendly Health Systems: Guide to Using the 4Ms in the Care of Older Adults

4Ms in cancer care

- High engagement of nurses

- Importance of quality improvement methodology

- "What matters most" facilitated advance care planning and knowledge about goals of care and prognosis

- Routine use of a GA proposed to achieve 4MS care

Hodge O, et al. Current Opinion in Supportive

Current PPC projects

- ## US Deprescribing Network Pilot
  - ### Facilitate deprescribing in older adults with dementia and their caregivers
- ## GEMSTAR NIA R03
  - ### Improve survivorship care plans and treatment burden in breast cancer care
- ## VA Merit Award
  - ### RCT Intervention study

Don't forget the GP!

Cohen HJ. J Am Geriatr Soc. 2009;57:S300–S302. .
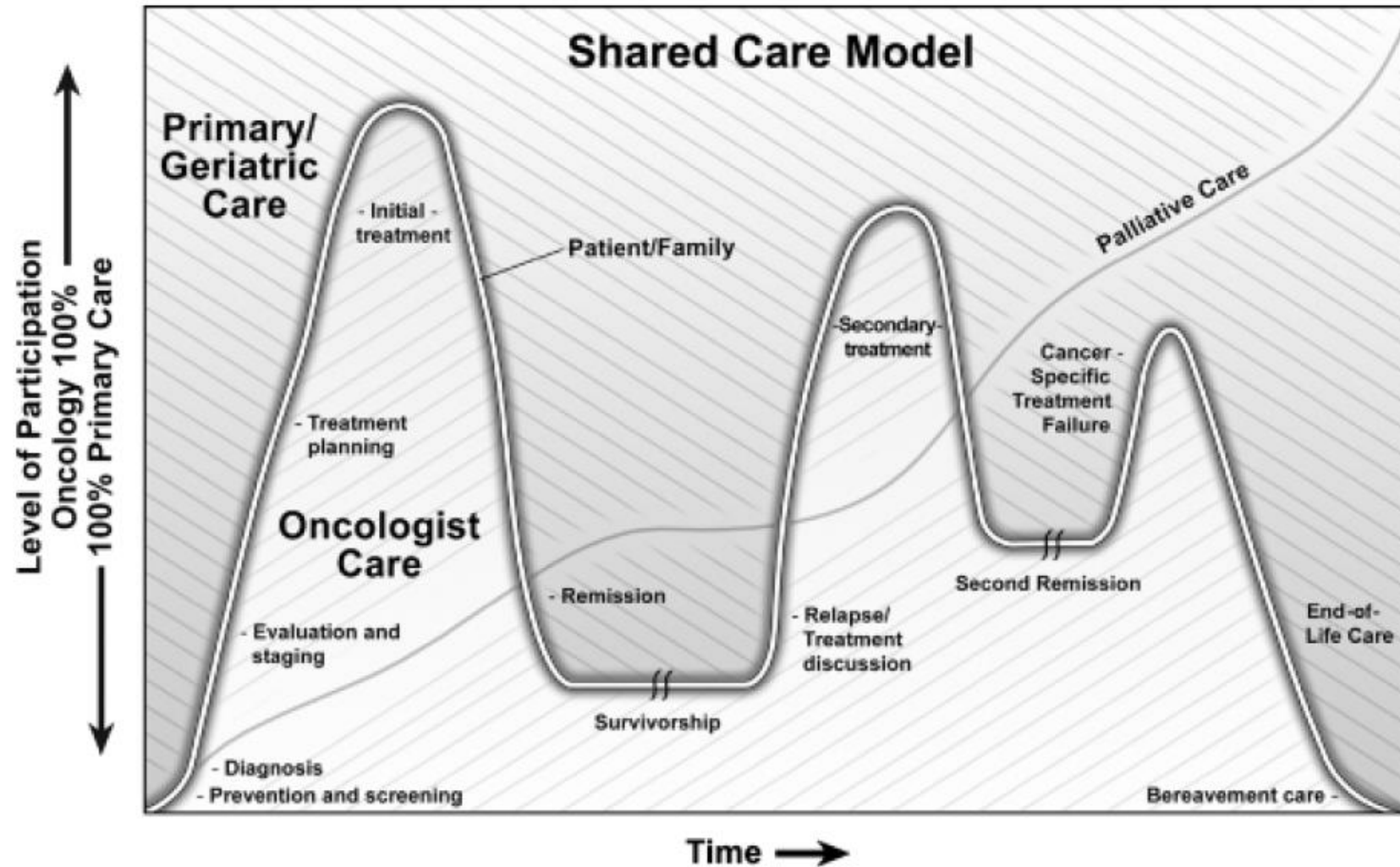
Thank you

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