

Practical Steps to More Effective ACP



Rebecca Kirch
EVP Policy and Programs
Washington, DC

@RebeccaKirch

Patient Advocate Foundation

Patient Advocate Foundation is a national 501(c)3 non-profit organization providing case management services and financial assistance to patients with chronic and complex conditions.



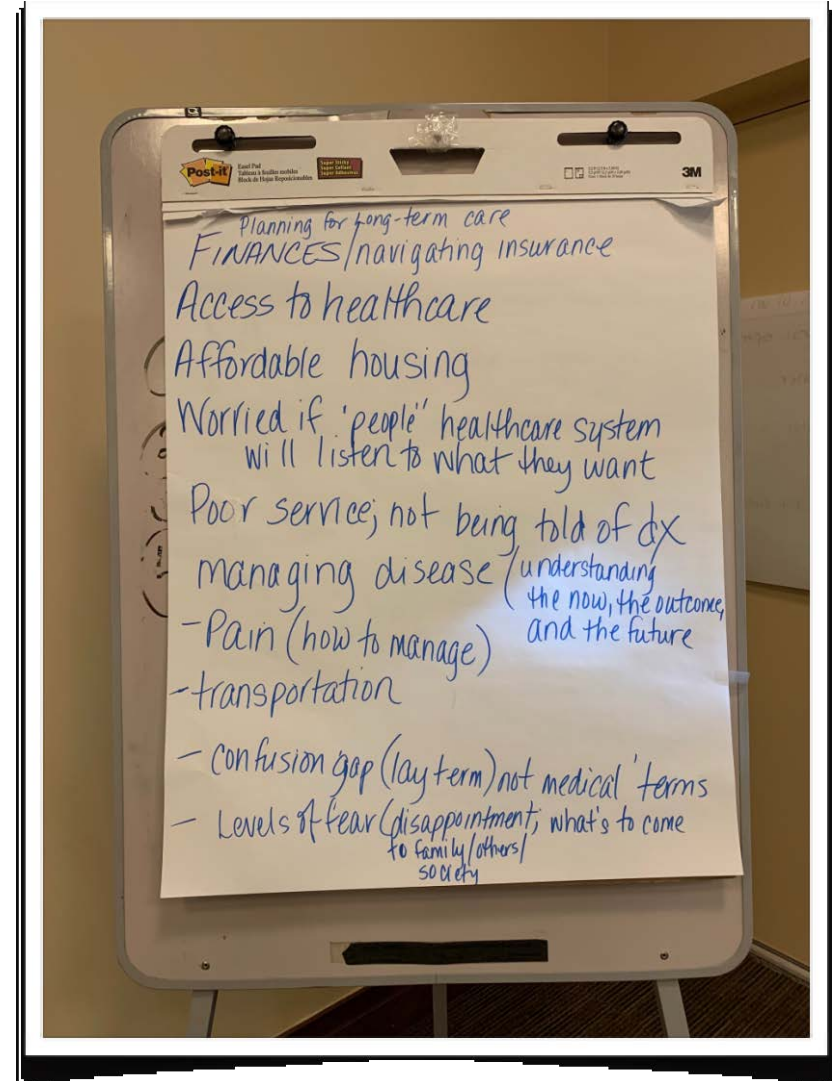
National Patient Advocate Foundation is PAF's advocacy affiliate representing patient and family voices coping with these conditions.



The untold back story

Patients confront a
constellation of concerns

- Insurance coverage
- Financial impairments
- Material hardships



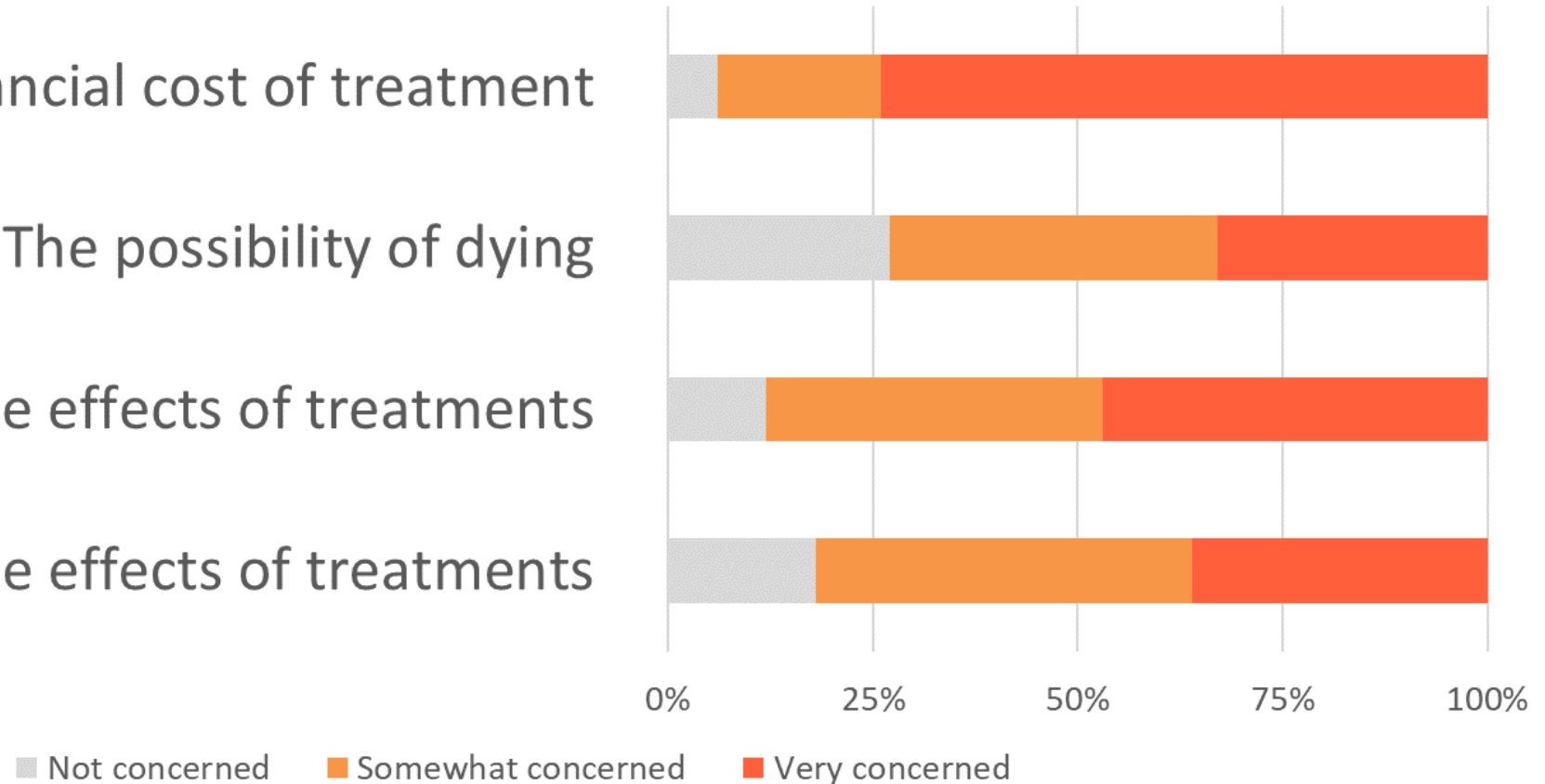
Top Concerns

The overall financial cost of treatment

The possibility of dying

Long-term side effects of treatments

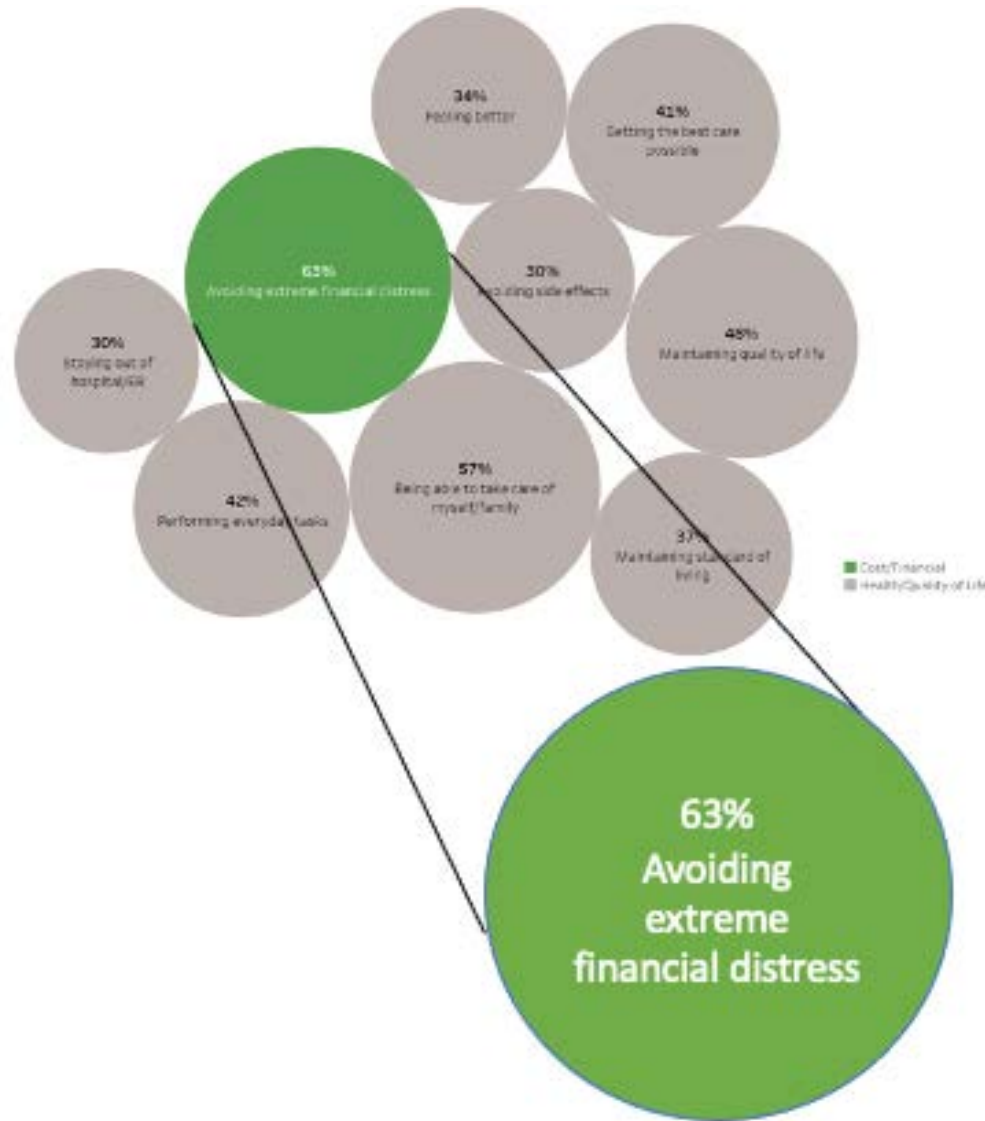
Short-term side effects of treatments



Impact of financial hardship

PAF patients ranked financial distress avoidance as their ***most important goal of care***

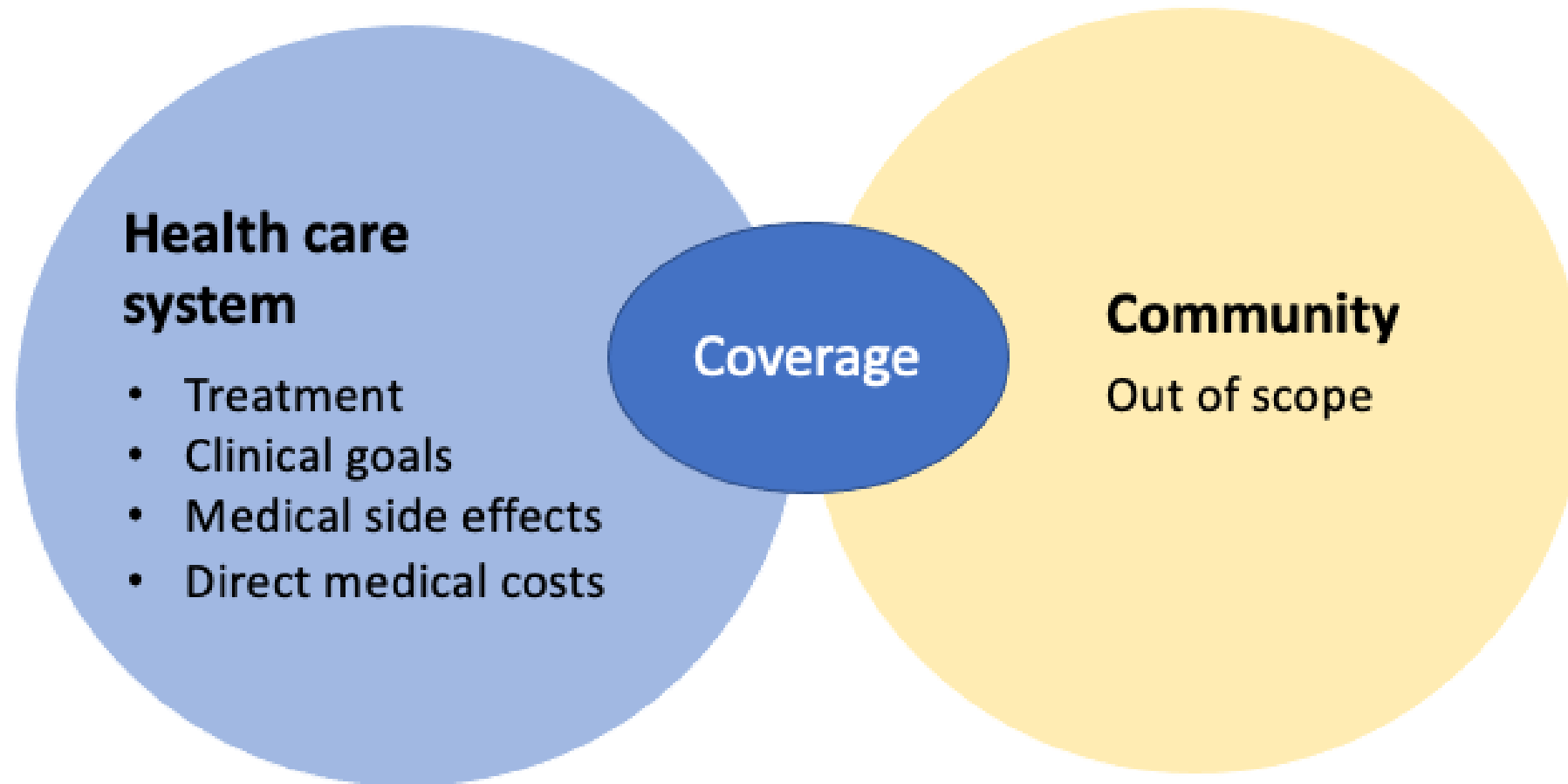
Ranked being able to take care of self and family second.



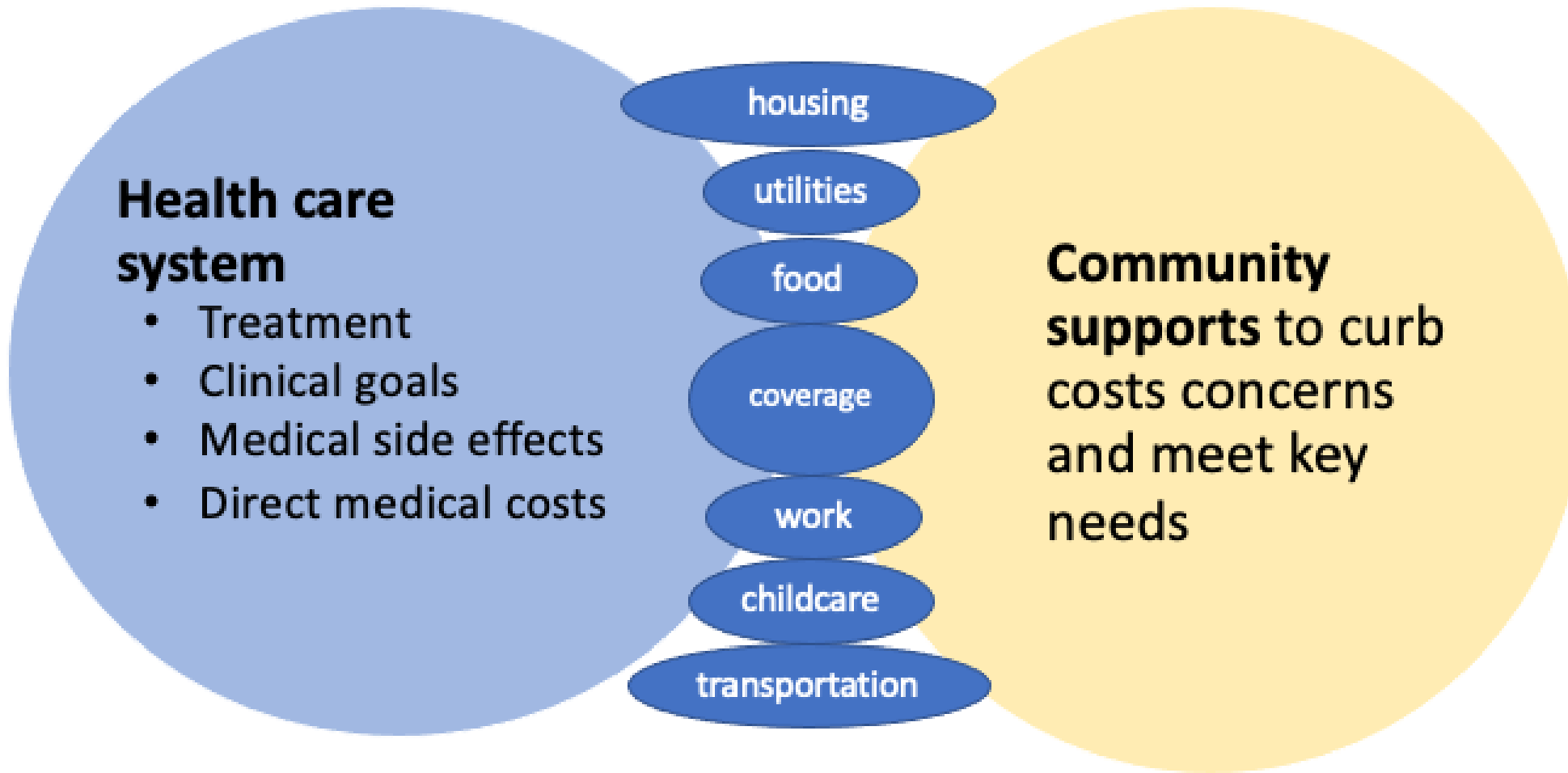
Financial and social needs are
often overlooked elements of
care planning conversations



Current health care model



Patient and family needs reality



Our lived experience



“What will it be like
when the other shoe
drops?”

Missed opportunity

- ✓ Got oncologist to request palliative care consult
- ✓ Readied parents (and daughter) to talk about care goals and pressing needs
- ✓ Secured inpatient family meeting with NP and SW before hospital discharge



Lessons learned



Everyone is
conditioned to
talk only about
their condition

How can I get my doctor to listen to me?



TALK ABOUT THE
CARE THAT MATTERS



TELL THE PEOPLE
THAT MATTER



Evidence to action: Policy considerations

1. People need relatable information to make good choices for them based on what they consider their top needs and concerns.
2. Caregiving is a major cost sharing and quality care delivery contribution that should be explicitly valued and supported.
3. Empathic communication skills and trust need to be built between patients and professionals through training and practice. *In both directions.*
4. Quality measures (and payment) should formalize accountability for person-centered communication skills training and practice that identifies patient's priorities and meets their needs.