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.

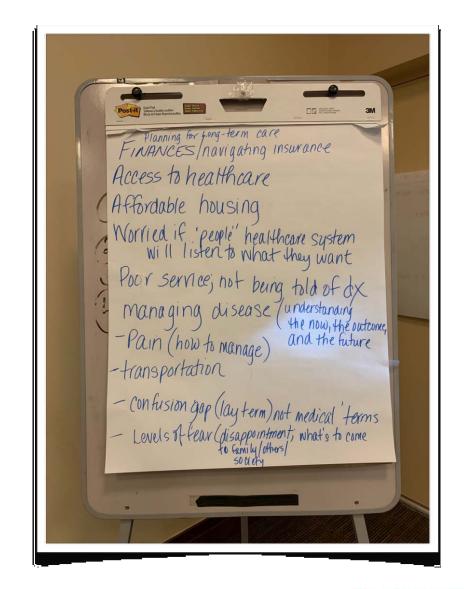


National Patient Advocate Foundation is PAF's advocacy affiliate representing patient and family voices coping with these conditions.

The untold back story

Patients confront a constellation of concerns

- Insurance coverage
- Financial impairments
- Material hardships





Top Concerns

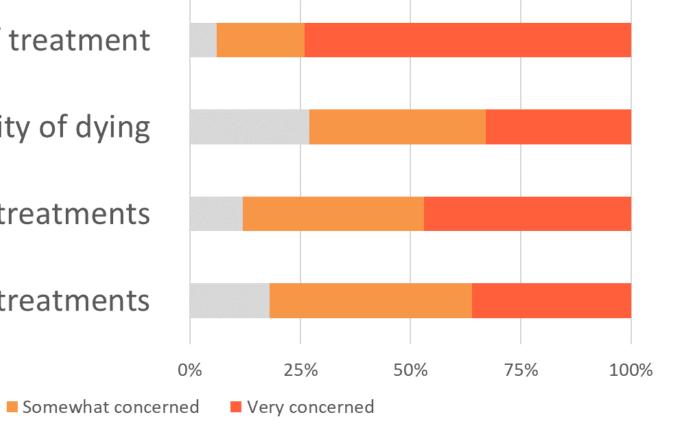
The overall financial cost of treatment

The possibility of dying

Long-term side effects of treatments

Short-term side effects of treatments

Not concerned





Detting the best care sing side effects Maintaining quality of hits. Straying out of haspitalisis Being able to take owe of 42% cryswitt family. Performing everyda (sei-Walnumingstagence ■ Cost/Tinancial III Health Classify of Life 63% Avoiding extreme financial distress

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

Health care system

- Treatment
- Clinical goals
- Medical side effects
- Direct medical costs

Coverage

Community

Out of scope



Patient and family needs reality

Health care system

- Treatment
- Clinical goals
- Medical side effects
- · Direct medical costs

housing utilities food coverage work childcare transportation

Community
supports to curb
costs concerns
and meet key
needs



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.

