



An Economic Perspective on Serious Illness Research

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A Few Numbers

People with serious
the physical

61% of people with serious illness reported at least one problem while receiving care, such as

understanding a medical bill or what their health insurance covered

being sent for duplicate tests or diagnostic procedures

getting conflicting recommendations from different health professionals



THE LEADING CAUSES OF DEATH
and Leading Drivers of the Nation's \$4.1 Trillion in

being left out,
isolated from others

Sources: CDC (2022); Schneider et al. (2018)

Economic Tradeoffs



- How do we make the best use of our limited research resources (time, money, etc.)?
 - What do we know and what don't we know?
 - Where can we get the biggest return?

High Quality Evidence



JAMA | Original Investigation

Association Between Palliative Care and Patient and Caregiver Outcomes

RESULTS Forty-three RCTs provided data on 12 731 patients (mean age, 67 years) and 2479 caregivers. ~~Thirty-five trials used usual care as the control, and 14 took place in the ambulatory setting.~~ In the meta-analysis, palliative care was associated with statistically and clinically significant improvements in patient QOL at the 1- to 3-month follow-up (standardized mean difference, 0.46; 95% CI, 0.08 to 0.83; FACIT-Pal mean difference, 11.36] and symptom burden at the 1- to 3-month follow-up (standardized mean difference, -0.66; 95% CI, -1.25 to -0.07; ESAS mean difference, -10.30). When analyses were limited to trials



Association Between Palliative Care and Patient and Caregiver Outcomes

A Systematic Review and Meta-analysis

“...palliative care was associated with statistically and clinically significant improvements in patient QOL at the 1- to 3-month follow-up...”

“limited to trials at low risk of bias ($n = 5$), the association between palliative care and QOL was attenuated but remained statistically significant...”

“associated consistently with improvements in advance care planning, patient and caregiver satisfaction, and lower health care utilization.”

Still lots we don't know



- Some important gaps:
 - External Validity: can we replicate the programs that show positive benefits?
 - Adoption: why are the programs with positive impacts not adopted?

External Validity



- RCTs have high internal validity but can face low external validity
- Although changing, older studies of palliative care were in highly controlled environments:
 - Academic settings
 - Not pragmatic

Improving External Validity



- Prioritize RCTS that are
 - Multi-site
 - Non-academic settings, with community partners
 - Pragmatic
 - Focus on a range of diseases and settings?

Improving External Validity



- Encourage quasi-experimental research designs
 - Can we provide real-world evidence with routine data
 - This work can be lower cost and more generalizable
 - Some effort to encourage this type of evidence warranted



Barriers to Adoption

- Need more work on barriers to adoption
 - Suspect that payment policy is a major barrier to health system adoption (outside of the hospital)
 - Is adoption higher where incentives are different?
 - What are the barriers (or facilitators) for patients and families?
 - What do patients and families want?



Barriers to Adoption

- What can we learn from settings where adoption is high?
 - International contexts
 - State and local programs and settings
 - Is payment policy the core issue?
- Do results replicate there and, if not, why?



Cost vs. Benefit

- Will palliative care save money?
 - That is not the right question!
- Does it bring value?
 - What is the cost vs. benefit?

Summary



- Aging of the population means that the need for serious illness care will only increase
 - Bodes poorly for the data shown at outset
- What evidence do we need to do better?
 - How do we move the needle on improving quality?